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Lost in Space: Service Users' Experience of Mental Illness

Marilyn Kendall

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A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy

Department of Sociology and Social Policy

University of Durham

2000

18 OCT 2000

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Service Users' Experience of Mental Illness

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Abstract

The aims of this study were to examine the experience of severe mental illness and of using mental health services from the perspective of service users, and to develop research methods that allow the voices of service users to be heard in academic and policy settings.

In order to achieve its aims, the study employed a variety of secondary sources in order to trace the development of mental health services in England from the beginning of the national lunatic asylum scheme in the early years of the nineteenth century through to the implementation of the community care reforms in the 1990s.

Having thus established the context for the fieldwork, the study adopted a qualitative research approach. Twenty-one adults with severe mental illness took part in a series of unstructured interviews. The participants came from a variety of backgrounds, but all lived within the same English county and were served by the same Health Authority and Social Services Department. Using the Nud.ist software package and the techniques of narrative analysis, the data generated in these interviews was explored in order to develop a fuller understanding of the participants' experience.

The study concludes that, once diagnosed with severe mental illness, people face a gap between their hopes and expectations and their actual experiences in relation to several areas of their lives: treatments and contact with professionals; social and family life; and economic activity. In addition, mental health policy and practice contains within itself conflicting and contradictory messages and remains dominated by health professionals and politicians, despite the increasing rhetoric around the importance of including user voices.

The study's overall conclusion is that the experience of living with severe mental illness can be seen as being "lost in space" because the "spaces", moral, social and economic, as well as physical, that society currently makes available for mental illness are uncertain, contested and a poor fit with service users' own perceptions of their needs. Service users' voices and tales are also "lost in space" and ignored in relation to the development of policy and practice. Inappropriate research methods can contribute to this.

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1. IN THE BEGINNING...

> *" When you are in the middle of a story, it isn't a story at all, but only a confusion; a dark roaring, a blindness, a wreckage of shattered glass and splintered wood; like a house in a whirlwind, or else a boat crushed by the icebergs or swept over the rapids and all aboard powerless to stop it. It's only afterwards that it becomes anything like a story at all. When you are telling it, to yourself or to someone else. "*

Margaret Atwood, "Alias Grace" 1996.

1.1 Introduction

Are you sitting comfortably?.... Then I'll begin.

These words signalled the start of childhood afternoons: 1950s children's radio, "Listen with Mother", suitable stories to educate the post-war young.

I loved stories then, and do so now. We live encircled by stories, both hostages to and makers of them. We all tell stories about ourselves and in so doing confirm ourselves. We fashion ourselves from the materials we find around us; the stories we hear from others; the stories others tell us about ourselves; our hopes, fears and fantasies. For many of us, myself included, those basic building blocks are, on balance, favourable. The stories I can tell about myself are reinforced by what my family and friends tell me and by the physical signs around me - a country cottage, a car, a job. I can lay claim to a desirable physical, social and moral space in contemporary England. At work, as a social researcher in an old university, paintings of past scholars in cap and gown, ancient buildings and continuing traditions help show me who I am and where my space is.

To understand the story of this thesis however, we have to imagine ourselves in other spaces and guided to them by very different signs and stories. For the old, the sick, the mad and the poor are placed in parallel universes; ones all too easy to fall into but hard to come back from, and from whence we hear their voices only dimly, if at all.

In our society, people with severe mental illness hear stories about themselves that centre around violence and dangerousness, failure and rejection, hopelessness and burden. When they look around them at the history of madness they see not serene and smiling scholars but chained and raving beasts, not gleaming spires and gowned processions but incarceration in overtly sumptuous country settings and interventions ranging from the whirling chair to the ECT Suite. Such are the signposts to their spaces.

In the 1950s, when I was a child, we could all sit comfortably and listen with mother, for stories then appeared clear cut and certain. They had fixed beginnings and happy endings, beautiful heroines and courageous heroes. They were stories about us and gave us the materials for our own stories. In the 1990s however, my own children listen to different, postmodern stories. Now there is a growing awareness of those people who were excluded from the old tales and increasing challenges to claims to authority and truth.

This thesis is concerned with stories and spaces, with uncertainty and confusion.

1.2 The background to this study

This thesis tells the story of a Ph.D. which I used to think began in a committee meeting. A high, bare room full of echoes, from past and present. Outside it is a blustery March afternoon and tall, leafless trees are swaying and stretching in the highly regulated grounds of an old, Victorian lunatic asylum. Only the vegetation is left to control now. The asylum is now a Trust [words, words]. Within the room, twenty earnest, White, middle-aged figures seated in a semi-circle, a sheaf of papers spread before them, focus upon a grey-suited man speaking and pointing to a white screen covered in figures. This is the Community Health Council's sub-group on Mental Health and I am its Chair.

Community Health Councils [CHCs] were established by act of Parliament in 1973 to "represent the interests of the public in the health service in their district." Its members are elected volunteers, drawn from various local authorities and voluntary organisations. I came to mine in 1990, via involvement in women's groups, environmental groups, local politics and the Pre-School Playgroups Association. At 37 I was its youngest member. Because my local area contained three old long-stay hospitals, then starting on the process of retraction and resettlement, the CHC had made working with them one of its priority areas. During my eight years as a member I must have attended hundreds of such committee meetings and found myself increasingly puzzled by them. Each presentation, complete with dazzling

overheads and glossy reports, painted a glowing picture of progress in all areas with community care, and yet when each was over I still could not understand how its plans would fit with those we had heard from a different department the previous month, nor how all this progress fitted with the increasingly distressing stories I heard from people who approached me for help and advice or with what the group saw on its monthly ward visits.

The debate about the advantages and disadvantages of a move to community based treatment and care for people with mental health problems was in full spate both locally and nationally. However there seemed to me to be a serious gap in the arguments because the voices and opinions of the very people whom it would most affect, and for whose good it claimed to be, i.e. those with severe and enduring mental health problems, were largely excluded.

In 1994, just as my youngest child started full-time school, I saw an advertisement for a Ph.D. studentship in mental health, sponsored by the Regional Health Authority for three years, full-time study. This seemed the ideal opportunity to undertake a study to plug this gap and to gather and examine from local people with severe and enduring mental health problems their experiences of, and views on, the move to community care.

However the process of carrying out this research led me to change my conceptualisation of the problem. Having set out to study service users' views on and experiences of what seemed to be a very important social policy change, I came, during the interviews and their analysis to realise that this was not the main issue for those participating in the study. I had already acknowledged that, in order to succeed in achieving its aims, this study had to be concerned with its participants' own understandings and meanings and their definitions of what was important in their lives. Taking these as the starting point for analysis, my own understanding of the problem under investigation began to shift.

The ways and terms in which the move to community care was debated in the forums to which I previously had access seemed to have very little relevance to the main issues and concerns for all those participating in the study. Regardless of where they lived and/ or received treatment and care, they continued to feel confused and disorientated by the conflicting messages they received about themselves and their place in our society and despairing about the possibility that they would ever again feel themselves to be valued members of that society; to be included as "one of us" not shut out, whether by physical walls or other more subtle barriers, as "one of them". Their concern with was identity, with maintaining a sense of "personhood". Barham has discussed this in his study of people with schizophrenia (Barham & Hayward 1991). In my study it proved to be equally important for people

with a range of diagnoses and receiving care in a range of locations. Indeed the distinction between hospital and community care also came to lose its force. As understood in the public debate, community care is something new, something that began with Mrs. Thatcher in the 1980s; the general understanding being that prior to that all people with severe mental health problems were mostly in long stay hospitals. Therefore the "problem" with this change to community care is two-fold; how to cope with those people now being resettled and how to cope with those people who develop severe mental health problems but now no longer have access to that pattern of treatment and care. However, during the course of the study it quickly became apparent that this distinction did not hold true. Some people had experienced in-patient stays of many decades, but others had managed mainly in the community with only relatively short in-patient episodes and some people, having developed problems only recently [within the last five years] had nevertheless spent most, if not all, of that time in hospital.

The community care envisaged in the policy documents from 1989 onwards was not only concerned with changing the location of care but also with changing the culture of care planning and delivery to one that is "user-centred"; where service planning starts from an assessment of individual need, services are provided to meet those needs, and service users and their carers are active partners in the process. Consequently this study was also concerned with discovering whether local service users were experiencing benefits from this culture change. Once again, however, the danger was that, by concentrating on the changes, which were keeping professional staff so preoccupied, the study might fail to address the equally important continuities that service users were still experiencing. This concern led me to re-interpret the issues around community care and user-led services in the light of the material which emerged from the interviews.

1.3 The aims and scope of the study

This thesis is about the experience of severe mental illness in the 1990s, as described by 21 adult people who live with it within one English county.

An immediate problem was the lack of an agreed definition of severe mental illness at the time when this study commenced. This had been highlighted as an urgent concern, given the government's declared aim of targeting resources on those who are most ill.

> The broad area of severe mental illness has suffered, in our view, from the lack of a clear working definition and it is time that one

> was agreed among those working in this field....An accepted definition is not an academic nicety, but is essential for identifying those people who are most vulnerable and ensuring that appropriate resources are available to meet their needs [1.11.] (Mental Health Foundation 1994).

Prompted by these concerns, the Department of Health had, by 1996, provided a definition.

> If services are to focus their efforts and resources on severely mentally ill people there needs to be a clear understanding of what is meant by "severe mental illness". There is no generally agreed definition, although many services have already developed their own operational definitions.
>
> In referring to "people suffering from severe mental illness" we mean individuals who;
>
> - are diagnosed as suffering from some sort of mental illness [typically people suffering from schizophrenia or a severe affective disorder, but including dementia];
> - suffer substantial disability as a result of their illness, such as an inability to care for themselves independently, sustain relationships or work;
> - are currently displaying florid symptoms or are suffering from a chronic, enduring condition;
> - have suffered recurring crises leading to frequent admissions/ interventions;
> - occasion significant risk to their own safety or that of others.
>
> [1.2.] (Department of Health 1996).

For the purposes of defining the eligibility criteria for inclusion in this study, only those people were recruited who were in receipt of services which were locally designated as being for people with severe and enduring mental health problems.

The aims of this study are:

- to examine the experience of severe mental illness from the perspective of adults living with it;
- to consider how, if at all, their lives have been affected by the policy change to community care;

- to look for evidence that the beneficial claims advanced in support of this policy change [the provision of user-centred, flexible and sensitive services; the development of empowering partnerships between service users and professionals; the opening up of opportunities for people to live a more normal and independent life with greater autonomy, choice and control, and to achieve their full potential] are being realised;
- to develop research methods that allow the voices of service users to be heard and acknowledged in academic and policy settings.

1.3.1 The national context

Mental ill health is widely seen as a huge national problem. As many as one in four of the population seeks help for mental health problems every year. Severe mental illnesses, such as schizophrenia or manic depression [also known as bi-polar disorder], affect up to four percent of the population (The Sainsbury Centre for Mental Health 1998). The numbers are approximate because the variations in definition and in ways of collecting data around the country make it difficult to obtain comparable figures.

The economic implications of mental ill health are correspondingly important. Recent estimates (Department of Health 1998*b*) suggest that some eighty million working days may be lost each year due to mental ill health, at a cost of around 3.7 billion pounds. 11,500 people are compulsorily detained in hospitals or mental nursing homes under the terms of the 1983 Mental Health Act and expenditure by the NHS and social services on mental health is about three billion pounds per annum. Two-thirds of the mental health budget for adults is still used for hospital care, for keeping a person in hospital costs about fifty thousand pounds per year.

Its human and emotional costs are vast. People suffering from mental distress all too often find themselves discriminated against and excluded from social, political and economic life. Consequently many people, in their despair, still commit suicide or harm themselves in suicide attempts. Approximately one quarter of the four thousand people who commit suicide each year are known to have been in contact with the mental health services in the previous twelve months. Finding ways to reduce this number has been, and seems likely to remain, one of the government's key public health targets (Department of Health 1992) (Department of Health 1998*a*) [forthcoming public health white paper]. Many others are harmed by the side effects of the powerful drugs offered to them as treatment.

1.3.2 The local context

The geographical area in which the study was undertaken is one of the largest counties in England, covering an area of approximately 3,200 square kilometres, varying from sparse rural populations to more densely populated communities, with declining heavy industry, some new light industry and service sector employment developing and much farming. Based on 1995 figures, it has a population of 307,000, with three fifths of that population living in one fifth of the geographical area. The population is 99.5 percent White (Northumberland Health Authority and Northumberland County Council 1996)

The social impact of both rurality and industrial decline may both be important in relation to the population's mental health, for significant links between deprivation and morbidity are well documented. Using indicators of deprivation and poor health, the south-east of the county has most deprivation and poorest health, but each part of the county has pockets of both. Male unemployment is, at 11.1 percent, above the national average [8 percent]

Health related behaviours such as smoking, drug and alcohol abuse, poor diet, lack of exercise and unsafe sex also affect both physical and mental well-being. Smoking levels and alcohol consumption in the county are known to be higher than the national average. Drug abuse has also risen significantly, particularly in the south-eastern part of the county. Suicide rates are also, at 9.75 percent, above the national average [8.95 percent]

Based upon national prevalence rates there are likely to be between 740 and 1,850 people in the county with schizophrenia and between 370 and 1,850 with other affective psychoses.

The county has one Health Authority, one specialist Mental Health NHS Trust and one Social Services Department, all co-terminous with its boundaries. The Trust and Social Services Department are nationally recognised for the progress they have made in joint working with many examples of joint budgets and particularly good practice in merging the Care Programme Approach [CPA] with Care Management. The Trust's Chief Executive is very accessible and committed to the value of, and practical development of, greater service user involvement in all aspects of service development and delivery.

There are 22 mental health User Groups in the county, co-ordinated and supported by two User Voice Workers, who are employed independently by the Community Health Council, although they are funded through a Health Authority contract with the Mental Health Trust.

At the time when the fieldwork for this study was undertaken [1996-97],

the Mental Health Trust was still in midst of its retraction and resettlement programme. The old long-stay hospital was still open and had 117 treatment beds and another 20 assessment beds for people aged over 65 and suffering from a functional illness. It was intended that the majority of the services currently provided on the hospital site would be reprovided in a new building on the same site.

1.4 The structure of this thesis

The following chapters of this thesis are grouped into three main sections.

1.4.1 Locating the research problem? Chapters 2,3,4.

These chapters outline and discuss the history of mental health policy in Britain from 1800 to 1996, in order to both locate the chosen research topic in its context and to explain its importance and relevance.

The discussion starts in 1800 with the background to the work of the lunacy reformers and the establishment of a nation-wide system of public lunatic asylums. This has been the chosen starting point because community care is perceived in opposition to such asylum care and therefore an understanding of the latter is important in order to appreciate the arrangements being offered in its stead. In addition, the establishment of the asylum system marked the start of the "age of confinement" in Britain (Foucault 1965), which Foucault has marked as cutting off the dialogue between the sane and insane, as distinguishing the two as different categories of person. Modern community care, with its emphasis upon not only a change in the location of care giving but also in its culture, is also concerned with attempts to re-establish this dialogue and re-conceptualise madness and normality as a continuum. The discussion takes as its finishing point 1996 because this was the year in which the fieldwork interviews were carried out and therefore the last year which the participants could include in their discussions, which form the basis of the findings of this thesis.

Chapter Two considers the troubled life history of the lunatic asylum from 1800 to 1960. Organisations are often considered to have a life of their own, influenced by both internal and external factors. Since the fieldwork for the study was going to be concerned with individual life histories, it seemed appropriate to consider the asylum in a similar way. In addition, the study came to be concerned with spaces of various kinds. Lunatic asylums adopted a number of very different physical, moral and social spaces for mental ill health in the course of, and sometimes, confusingly, contemporaneously

within, their lifetime.

Chapter Three examines the mysterious case of the [supposed] development of community care for people with mental health problems from 1930 to 1990. If asylums had adopted many different shapes and spaces, it often seemed that community care adopted none at all, existing in words only. As the spaces occupied by the asylums began to shrink and disappear, service users were hard pressed to discover the new physical, moral, social and economic spaces designated for them.

Chapter Four discusses the growth of public involvement in a range of services and the rise of a rhetoric within the health and welfare services of the provision of "user-centred services". The chapter considers both the growth of new social movements in general and of a mental health service users movement in particular. It examines whether the new community care culture is being implemented in practice and, if so, what new spaces and relationships it might provide for mental health service users.

Taken together these three chapters highlight and discuss the main policy issues and ideas of relevance to this study. These were further developed, and linked with additional literature, in the light of material generated during the interviews with current service users. This is discussed in chapters 6 -10.

1.4.2 Investigating the research problem: Chapter 5

Having thus located the research problem in its policy context and highlighted the contested nature of mental illness and of society's response to it, this chapter locates the methods chosen to investigate the research problems in their social research context. Given the aims of the study, the current menu of available research methods and approaches, and my own philosophical stance, which is based upon an idealist ontology and an interpretivist epistemology, a non-standardised, qualitative approach was adopted. This aimed to allow space for the participants' own perceptions, accounts and stories to guide the study's development through a series of unstructured interviews with each person. These would be tape recorded, fully transcribed, and analysed with the aid of the Nud.ist computer software package and the techniques of narrative analysis.

The chapter gives an account of the process of applying these methods during the fieldwork undertaken for the study and highlights the lessons learned from this. Just as my conceptualisation of the main research problem shifted during the period of the study, so also, in ways closely linked to it, did my understanding of the methods of social research. My growing realisation of the ways in which the aims, methods, findings and outcomes of any study are always and inevitably interlinked shifted the focus of decisions about

research methods from the merely technical to a central place in the story of this thesis. At each stage of the research process it was vital to adopt an approach that allowed participants' voices, understandings and concerns, as expressed in the interviews, both to be heard and to be transferred into an academic text.

1.4.3 Relocating the research problem: Chapters 6,7,8,9

As the interviews progressed, some key themes began to emerge, which were used to guide and inform the coding process. Whilst it is obviously not possible to include all the areas discussed within one thesis, it was also apparent that the main concerns and issues of importance to the participants were much broader than simply the provision of services. Consequently each of these chapters focuses upon a particular key area from this range of concerns.

Chapter Six discusses the participants' experiences of, and views on, their contacts and relationships with a wide range of mental health professionals. Chapter Seven examines their views concerning the treatments available to them and the difficult judgments they are faced with in deciding whether or not to take them. Chapter Eight considers the ways in which the participants fill their days, particularly their hopes for employment. Chapter Nine reflects the participants' views on their social relationships with family, friends, acquaintances and the general public; in particular what this tells them about themselves, the value of their lives and their place in our society.

Chapter Ten concludes the study by bringing together the main findings from each of these three grouping [mental health policy, research methods, interview data]. It considers the ways in which the various findings interlink and can increase our understanding of the experience of severe mental illness and the needs of those who live with it. Finally the chapter considers the implications of this for future research, policy and practice.

1.4.4 Postscript

Now, as the writing of this thesis draws to its close, I have come to increasingly question any certainty about beginnings and endings, or even whose concerns this story reflects. Freezing thought into words and text may mark out a point within an on-going story, or stories, but is unlikely to form the definitive statement about its subject matter for all times and all audiences.

In addition, the conventions of research texts still often assume a separation of the researcher and the participants in any study. The argument

developed in this thesis is based on what those who participated told me about their lives, but is also grounded in and through my own life and values and, thus, my particular approach to their accounts. It offers my interpretation of their interpretations. However carefully researchers attempt to access other people's experience, this can only be done through the filter of that researcher's own perceptions. Nevertheless I do believe that there is much value in such attempts and in acknowledging the difficulties that surround them. My own perceptions have been at least partially shaped by my love of, and continuing interest in literature, undimmed by ten years spent as a teacher of English in comprehensive schools. Consequently I have included some literary extracts in this thesis.

2. THE TROUBLED LIFE HISTORY OF THE LUNATIC ASYLUM:1800–1960

" en ma fin git mon commencement
[in my end is my beginning] "

Mary, Queen of Scots, 1542 -87

2.1 Locating the research problem?

Chapters Two, Three and Four of this thesis are concerned with locating the study's research problem. As originally conceived, this was to examine and explore service users' experiences of, and views on, the move to community based treatment and care for people with severe and enduring mental health problems. Consequently these chapters provide the historical and policy background to this change in social policy.

Since the chapters are structured around a thematic, rather than strictly chronological framework, there is some duplication in the years which they cover, which allows each chapter to focus on a particular part of the developments then taking place within mental health services.

During the course of the fieldwork for the study the research problem was repositioned in the light of the material generated by the interviews with service users. Discussion of the additional literature which was consulted during and after the interviews is therefore contained in Chapters Six, Seven, Eight and Nine.

2.2 Introduction

This chapter will trace the life history of the lunatic asylum from its uncertain conception in the early years of the nineteenth century until the beginning of its demise in the 1960s.

The asylum's story during this period plays a vital part in locating this study's research area. This thesis has a major concern with the spaces allotted to people living with mental distress and for many decades the asylum's walls physically and morally marked out the officially designated space for mental illness in Britain. The asylum provided a space for people who had been categorised as essentially different from those outside it and, by withdrawing those people from the rest of society, shut them up both physically and, by excluding their voice from all public debate [the mad had no voting rights], from dialogue with the separate world of the sane. However the shape of, and space enclosed by, an asylum was itself contested and changed over this period as politicians, psychiatrists, policy makers and the public, but very rarely people with mental ill health themselves, debated the nature of mental illness and its treatments.

This chapter will give an account of the rise and dominance of the asylum as a suitable space for treatment by tracing the debates, discussions and arguments which contributed to the initial decision to categorise and shut away the mad and to the consequent decisions to keep them so until the middle years of this century started to give greater emphasis to those who wished to see the asylums dismantled and the mad once more brought back into society.

Until recently, the dominant public image conjured up by the phrase "mental health services" was that of the large Victorian asylum, set in spacious grounds away from the city centre and inhabited by strange and unfamiliar people with shuffling gait and averted gaze and given to unpredictable and even violent behaviour. That image is an enduring part of the legacy of the Victorian asylum, and it is in opposition to that image that the vision of community care, or community mental health services, has developed. Indeed it is the reason why it is now necessary to provide the prefix "community". Consequently it is still important to remember the history behind the asylum, since its image–true or false–still colours so much contemporary discussion of mental health services. As Bynum says:

> it would be historically wilful not to give a certain pride of place in the annals of madness to the defining role played by the asylum (Bynum, Porter & Shepherd 1988).

In addition, several of the people who took part in the interviews on which the findings of this study are based had themselves experienced long in-patient stays [several decades] and this is reflected in their discussions.

2.3 A difficult birth: 1800–1850

The nation-wide, publicly funded lunatic asylum, now metamorphosing into executive housing estates, was born in England in 1845. Its immediate progenitor was Lord Ashley, later the seventh Earl of Shaftesbury, who was the prime mover behind the passing of the 1845 Lunatics Act, which made the erection of county and borough asylums compulsory. Its immediate ancestors were the private madhouses and charitable asylums.

The private madhouses, established from the mid seventeenth century onwards, offered mainly custodial care for the disturbed, difficult and unwanted from both the rich, at their own expense, and the very poor, through public funding. The charitable hospitals for the insane were established in the eighteenth century and served those in the middling classes and the respectable poor.

The precise details of the public asylum's conception, gestation and birth remain contested and shrouded in uncertainty. This period of asylum history has been written about during the past decade by a number of historians, such as Scull (Scull 1993), Busfield (Busfield 1986), Donnelly (Donnelly 1983), Jones (Jones 1993), Micale and Porter (Micale & Porter 1994), Arieno (Arieno 1989) Bynum et al. (Bynum et al. 1988) and Rogers and Pilgrim (Rogers & Pilgrim 1996), whose work has influenced the substance of this chapter. From this it is apparent that, despite difficult beginnings, in the political, social and economic climate of the ensuing years the asylum quickly grew to gargantuan proportions, swallowing up nearly all of its competitors. It was, however, a thoroughly human conception, inasmuch as the asylum did not, like the goddess Athene, who sprang fully formed and clothed from the head of Zeus, suddenly appear as a complete entity, its form and functions clear and undisputed. Rather its birth was long, painful and subject to many, often competing, internal and external pressures: a situation which was to be repeated in the following century with the equally difficult and problematic birth of the community mental health services.

In order to understand more about the asylum's nature, it is necessary to place its birth in the wider context of early nineteenth century society and thought, where other dramatic changes were also taking place. In the 1750s, the vast majority of the insane were still to be found in the community, or perhaps in workhouses and jails, and were thought of simply as part of the larger, and more amorphous class of needy persons unable to care for themselves. One hundred years later, however, they had been clearly and sharply distinguished from this larger grouping and many were now confined within a specialised, bureaucratically organised, state supported asylum system, that isolated them, both physically and symbolically, from

the rest of society. Their condition had, by then, been diagnosed as being uniquely and essentially a medical, rather than a social, problem, which necessitated their being cared for by the new professional group of the "mad doctors" (Scull 1993).

How had this change in perception and practice come about? The Lunatics Act of 1845 was but the culmination of a series of Acts passed during the early years of the century dealing specifically with lunatics. This insanity legislation was, in its turn, but part of an increasing state intervention in social problems, encompassing such areas as Poor Laws, Factory and Mine Acts and Public Health Acts: and all such legislation had its roots in the changing nature of an increasingly industrialised and urban society which found itself less able, and/ or willing to integrate the mad into ordinary society (Busfield 1986).

From 1800 onwards a campaign had been gathering pace aimed at reforming the existing arrangements for lunatics, both within and outside the Poor Law system. The reformers were seeking greater regulation of, and control over, the existing asylums and madhouses and the provision of public asylums for the pauper insane. Their work was, overtly at least, driven by the belief that much of the existing provision was inadequate in terms both of quantity and of quality, and that this was often because of the associated profit motive–the so-called "trade in lunacy" (Busfield 1986). They brought to public attention examples of maltreatment, overcrowding, lack of staff and inappropriate mix of patients to support their claims that the existing system was a failure: problems and cries of "failure!" that have persisted to this day.

2.3.1 Differing views on insanity

At the same time as this backdrop of criticism and scandal was developing, views on the nature of insanity were also changing.

Although the insane were affected by earlier legislation, such as Poor Laws and Vagrancy Acts, these did not necessitate their being defined as a separate group, nor any close examination of the variety and severity of their disorders. Such provision as there was for them served mainly to prevent them from harming themselves or others and there seems to have been little idea of any possibility of a cure for them.

At that time insanity was viewed as being mainly defined by an absence of reason, as likely from a theological or supernatural cause as from a physical or psychological one. This lack of reason placed the sufferer on a level with animals and made it seem legitimate to treat them like animals. Indeed they were often kept in chains, alone, naked and in filthy conditions. Any treatments offered specifically for insanity [as opposed to the more general

purges etc.] were things like whipping, or immersion in cold water, which were designed to purify the body and shock it back into an acceptance of reason.

However new ideas, rooted in an increasingly anthropomorphic account of the world and of man's [sic] active role in and power over it, and in scientific developments such as Comte's biological positivism, contributed to a change in this view, described by Scull as, "a transformation of madness into mental illness." (Scull 1993). Those working for lunacy reform incorporated these ideas, arguing for a view of the insane as still essentially human but lacking in self-restraint and self-discipline and of insanity as a disease of the body and amenable to treatment and cure. Nevertheless, then, as now, the distinctions, definitions and arguments were never entirely clear or clear-cut. Within the ranks of the lunacy reformers were men who held to either, or both, of the two broad models of madness, the medical and the social, and both the scientific and the religious discourses persisted.

2.3.2 Differing views on treatments for the insane and opposition to the lunacy reformers

Dissatisfaction with the existing arrangements, coupled with arguments for a new paradigm of insanity lent strength to the reformers' case for a system of state funded asylums as the best space for the insane: a case no doubt pleasing to society, which could thus both see this problem population removed from their midst whilst being told that it was in the insane's best interests to do so.

Given the competing views as to the nature of insanity, it is no surprise that there were also competing, and changing, views as to how it should best be dealt with, exemplified most clearly with the founding, in 1796, by the Tuke family, of the York Retreat, based on a regime of "moral management". The Tukes' work arose as a reaction against what seemed to them to be the harsh methods employed in private and voluntary asylums and madhouses. The people who found themselves there tended to be those who were the most violent and difficult to manage, since asylum care was more expensive than the other options and so, usually, the last resort. The cheapest and simplest method of dealing with numbers of such people was by means of physical or mechanical coercion.

By contrast, the principles of"moral treatment", as enacted at the York Retreat, were based on the concept of a small and homely asylum where up to 100 people could be individually known and cared for by kindly and dedicated staff on wards containing no more than 10 people. The setting,

design and environment of the asylum themselves formed an important part of the treatment, as did the opportunity for useful work. Indeed, moral treatment was not so much a specific treatment as an overall approach that aimed, by various means, to provide a calm and comforting refuge where the insane could be encouraged to reassert their own individual powers of self control and nature could be enabled to effect her own cure.

It was this model of asylum care that the lunacy reformers wished to see nationally adopted. They argued that, although expensive to establish and run, it offered the prospect of a cure and return to productive life. However, they also stressed that this could be achieved only in purpose-built asylums, used as a place of first, not last, resort and run under medical supervision. Since the existing mad doctors would view the proposed asylum system as a threat to their livelihood, negotiations with them devised ways in which this scheme could be assimilated by them. However, doing so, although it aided the passing of the necessary legislation, only contributed to the ill-defined birth of the asylums.

Indeed there was opposition to the asylum scheme from a number of powerful groupings with a vested interest in maintaining the status quo. The owners of the existing madhouses tried to rebut the criticism of their provision in order to protect their source of income. Some medical practitioners were opposed to the increase in state intervention in their work which they foresaw would accompany such a centrally managed scheme. Local aristocrats and magistrates also resisted the move, which they saw would undermine their control over local provision and compel them to comply with nationally issued orders (Scull 1993, Donnelly 1983).

Nevertheless, the supporters of reform,–an influential group of aristocratic philanthropists, new entrepreneurs, some mad-doctors and Quakers–proved more powerful at this time and the Act was passed, albeit with less than unanimous support.

2.3.3 The 1845 Lunatics Act

The passing of the Act:

- compelled every county and borough in England and Wales to erect an asylum to house pauper lunatics;
- established the insane, for the first time, as a separate group, defined by their mental disorders;
- established a single, statutory authority, the Commissioners in Lunacy, to be centrally responsible for them, whereas they had previously been

> subject to only their immediate keepers, whether in jails, workhouses or private madhouses. These commissioners had the authority to inspect and monitor all asylums and to make decisions on the proper treatment. for the insane.

The Act thus established the national system of lunatic asylums and, in its wake, the division of hospital services into separate general, chronic and mental institutions, which persisted until the 1950s. Beyond this, as many commentators have noted, the new lunatic asylum system also helped to establish the dominance of a medical and biological view of madness; a madness which doctors were therefore best placed to manage.

> The 1845 Lunatics Act sounded the death-knell of lay administrators by awarding a monopoly of the running of institutions to medical practitioners. The term "psychiatry", which was introduced into British medicine for the first time in 1846, is evidence of the link between the 1845 Act and the emergence of a subspeciality of medicine (Rogers & Pilgrim 1996).
>
> These institutions became the linchpin of nineteenth century mental health provision and the places where psychiatry clearly emerged as a separate speciality within medicine and where madness was transformed into mental illness (Busfield 1996).

The complex beginnings of this asylum era were rooted in a society, then as now, both struggling to understand the nature of mental illness and how to treat and provide for it and also, as Scull has argued, subject to the effects of broader structural and cultural changes:

> The genesis and subsequent development of specialised segregative techniques for the handling of the mad was neither fortuitous nor the product of the mere piling up of a series of incremental, ad hoc decisions which were bereft of any underlying dynamic or logic. Instead the trajectory taken by lunacy reform in nineteenth century England must be seen as the product of historically specific and closely interrelated changes in that society's political, economic and social structure; and of the associated shifts in the intellectual and cultural horizons of the English bourgeoisie (Scull 1993).

In 1845, as the lunacy reformers eagerly awaited the birth of the County Asylum system, what they hoped to see born was a nationwide network of

small [100-250 patients], purpose built asylums, run on the principles of moral treatment, that would provide a cure for their specialised client group [those in the early stages of mental illness], under the supervision of specialised doctors. Their child, however, like most, grew rapidly and in ways of which they did not always approve.

2.4 Adolescent anxieties and middle-age spread: 1845–1900

As early as 1850 most pauper lunatics were now to be found within public asylums. 24 had been built, each with an average population of 297 patients, thus already exceeding Tuke's ideal size of no more than 100 (Scull 1993). Indeed, the reformers' initial vision had already undergone dramatic and far-reaching changes, not least because the promised cures were not forthcoming. The reformers claimed this was because their work was undermined by the fact that people were still not sent to them at an early enough stage in their illness. Whatever the cause, the result was that the asylums rapidly filled up with chronic cases. To carry on building more and more of the small, model asylums was becoming more expensive than society was prepared to tolerate, not only with regard to the actual costs on their taxes but also in the sense that there was a growing fear that being insane could come to be seen as a desirable, rather than a stigmatising, state.

In order to compensate for the unexpectedly high level of demand for asylum places, those things which many regarded as unnecessary frills and luxuries and wasted on the insane began to be abandoned. The first casualties were the comforting and calming style of architecture and the emphasis on small scale asylums. Extra, and larger, wards were built on to the asylums, often with separate and less costly accommodation for the chronic cases, and strict rules, discipline and regimentation were introduced to cope with these increased numbers.

The reasons for the transformation of the asylum system in its early years are many, varied and interlinked, but they highlight many of the difficult tensions always inherent in the scheme.

2.4.1 A rapid growth

A rapid increase in their size was the most obvious and visible sign of change in the early asylums, and the one that the reformers resisted most strongly. They believed small asylums were a necessary condition for cure. Employing arguments now more familiar to present-day readers in support of community

care, the reformers claimed that only in small asylums could patients be offered the vital individualised care in familial, household-like surroundings. However local magistrates, poor law officials and communities, faced with an ever increasing demand for asylum places and little evidence of the promised cures, saw rather the possibilities for economies of scale and the average size of county asylums grew almost yearly until well into the twentieth century. John Connelly, one of the foremost of the reformers, wrote in 1871,

> the magistrates go on adding wing to wing and storey to storey....rendering the institutions most unfavourable to the treatment of patients and their management most harassing and unsatisfactory to the medical superintendents (Scull 1993).

This unrelenting growth did indeed have profound implications for asylum management styles and for the role of its staff.

The Lunacy Commissioners had predicted a fall in the numbers of the insane in their 1847 report:

> The present humane method of treating the insane and the provision made, at the public cost, for pauper lunatics of asylums furnished with every comfort....promise to diminish the numbers of the permanently insane (Arieno 1989).

However, an article in The Scotsman [1.9.1871] read:

> build as we may, in every succeeding year we find the same demand for further accommodation....a work which shows as little promise of coming to an end as that of filling a bottomless pitcher....Instead of finding that the great outlay which has been incurred in erecting asylums has led to the decrease of insanity, we find, on the contrary, an enormous and continuous development (Scull 1993).

This rapid growth in the number and size of the asylums reinforced public views of madness as a long term, hopeless condition and contributed to fears that there was an epidemic of madness in the country. Never wholly convinced by the reformers' arguments, nor ready to provide from their taxes for the best quality accommodation for the insane, public support for the model asylums quickly evaporated.

2.4.2 The influence of the Poor Law system and of admission and discharge procedures

Another major factor that influenced the nature and character of the public asylums in their early years was the fact that they were firmly situated within

the wider, and often opposing, concerns of the Victorian poor law system. They were built, maintained and run at public expense and considered an expensive option in all three areas. Poor law officials were quick to point out the comparative costs of keeping the insane in an asylum as opposed to a workhouse, workhouse rates being approximately one third of those of the early asylums. Many local authorities had been reluctant to provide any asylums at all until forced to do so by the 1845 Act and there was, from the outset, tremendous external pressure to keep costs down. Consequently many of the aspects of size and moral treatment advocated by the reformers came immediately under pressure from those, only reluctantly, implementing them.

In addition to this constant pressure for economy, the asylums' situation within the poor law also affected the numbers and characteristics of its patients and staff. Poor law officials wished to send to the asylums those whom they found most troublesome or expensive to maintain in the workhouses, rather than those who might seem to offer the best hope for a cure. In any case, the underlying philosophy of the 1834 Poor Law was that of deterrence and of relief as a matter of last resort. Consequently it was difficult to gain admission into the poor law system at all, let alone to be maintained in an asylum rather than the cheaper option of the workhouse. It was always going to be very difficult to reconcile this style of working with that needed for the successful running of the new asylums (Busfield 1986). The reformers regularly complained about this and its contribution to the failure of the curative ideals of the new system. In turn, working in a public asylum with such hopeless cases did not offer an attractive or high status occupation for staff. This too is a problem which continues to this day.

From the outset the new asylums had legal powers of control over their patients and so the admission and discharge procedures were the responsibility of the local magistrates and required certification. This tended to give a custodial character to the asylums. Since clear evidence of insanity or recovery were needed, this also undermined the curative aspects of the asylum, which required a clientele of recent cases of insanity, where such clarity might be hard to establish. It likewise made discharge more difficult, thus contributing to the blocking of the available beds. The asylums' legal powers also affected the style of their buildings and management by emphasising a concern with security.

2.4.3 Management styles and staffing issues

As the asylums therefore developed as large institutions set within a custodial and poor law, rather than a medical, framework of admission and discharge,

their management styles also evolved in ways which concentrated on the maintenance of good order and smooth running. The staff developed detailed rules and codes to enforce the necessary discipline but, in the process, destroyed any possibility of implementing moral management as originally understood. As Scull points out,

> the degree of regimentation needed to administer an institution of 600-1,000 inmates ensured that asylums would be the virtual antithesis of their supposed inspiration, the York Retreat. To Tuke moral treatment had meant the creation of a stimulating environment, where routine could be sacrificed to the needs of the individual. Here the same term disguised a monotonous reality in which the needs of the patients were necessarily subordinated to those of the institution; indeed where a patient's needs were unlikely to even find expression (Scull 1993).

This type of management style led to the introduction of a system of separate wards and elaborate classification of patients, which further contributed to the custodial character of the asylums. The moral treatment system which had originally aimed to allow patients to develop their own internal self-control and discipline turned into one that imposed control externally by regimentation and routine, the classification of the patients being not for the purposes of medical treatment–there was very little of this–but only for ease of managing them.

This provides another example of the huge internal tensions contained within the asylum project. A major concern for both the public and asylum staff was to ensure order and control, yet patients often found themselves in the asylums precisely because they had failed to exhibit such order and control in their daily lives in the community or workhouse. These specialised asylums had been established because of acceptance of the argument that lunatics were sick and not responsible for their actions; yet they now found themselves in vast institutions that could function only if they conformed to a strict code of rules.

The asylum staff had therefore to adapt their working practices and ideologies to a changing role. In a small model asylum, the medical superintendent and doctors could be personally involved in each individual patient's care but, as the asylum grew, so the medical staff became more remote and ranged in a complex hierarchy.

The superintendent's role came to involve a heavy workload of administration, such as keeping detailed casebooks, journals and registers, which in itself reduced the time available for spending with patients [a complaint still commonly heard about and among mental health professionals: see Chapter

Six]. Although he [for they were all men] remained a powerful figure within the asylum, his work increasingly took place within an arena whose limits and conditions were set by others. Especially important here was his lack of control over admissions, discharges and funding levels. Although the job had its attractions, the facts that its clients were paupers and that the superintendent had to reside within the asylum with them conspired to lower its status, particularly once the reforming zeal and enthusiasm of the early years had passed. This in turn meant that the post tended to be able to attract only the less powerful and dynamic doctors, who were then at a disadvantage when in conflict with local authorities or Boards of Guardians over decisions concerning the nature and running of the asylum. The evidence is that, by the end of the nineteenth century, many superintendents had given up the battle altogether and were not paying even lip service to the principles of moral treatment (Scull 1993).

As a new profession, the asylum doctors had their own worries. If unable, in the current circumstances, to produce the promised cures, the understandable pressure on them was to, at the least, demonstrate the continuing large demand and need for their services. In such a scenario they too might well be reluctant to discharge even chronic cases and prepared to change their criteria of success; successful asylums came to be defined as those that could exhibit cleanliness and good order, rather than a high rate of cure.

That such changes in ideology and practice came about reflects the difficulties always encountered when trying to implement a new view of patients or conditions, rather than simply a new style or location of building or a new range of treatments. The medical staff were also men of their times, their own thinking and practice having to take place within, and moulded by, a society whose dominant ideology of madness and of welfare provision was very different from that of the early lunacy reformers.

For the attendant staff also these years brought many changes. As the medical staff became ever more remote, the attendants' role became more important in the patients' everyday lives. However, for them too, the changed character of the asylum made working there a less attractive prospect and it became increasingly difficult to recruit and retain the high quality staff that their role demanded [still a familiar problem today]. There was never any formal training or recruitment of attendants, despite acknowledgement of the importance of their role. Indeed, one contemporary source described them as:

> the unemployed of other professions....if they possess physical strength and a tolerable reputation for sobriety, it is enough; and the latter quality is frequently dispensed with. They en-

> ter upon their duties completely ignorant of what insanity is (Busfield 1986).

Such a situation is hardly surprising given their low rates of pay, long working hours and poor conditions and it too contributed to the failure of the early curative hopes for the new asylums.

Over these years even the patient's role changed: from being a person suffering from some form of the disease of insanity, who could enter an asylum for a short period for treatment and cure, he, or increasingly she (Busfield 1996), became a mere object for containment and research. Having large numbers of lunatics gathered together and under close supervision made them ideal objects for the research ambitions of the medical staff. Large numbers of post-mortems were carried out to search for physical manifestations of disease, influenced by current medical models of the disease process, and careful records were kept of all aspects of the asylum for later analysis.

The reality of daily life on the wards by this time was revealed, amongst other cases, at the Lancaster Asylum in 1870, when two attendants were convicted of the manslaughter of a patient (Bynum et al. 1988). Evidence given in the case revealed that violence towards patients was common, so much so that there was no point in bothering to report it, that fights and the use of mechanical restraint were common and that medical supervision was almost non-existent: an experience that many people could still describe today [see Chapters Six and Seven]. In fact there had been a return to many of the conditions that the reformers had sought to eliminate only 25 years earlier. Gone was their vision of a dedicated and inspiring superintendent in close and daily contact with a team of keen attendants with a shared goal of achieving a cure through moral treatment.

2.4.4 Criticisms and proposals

These changes in the asylum's role and nature did not go unchallenged. Although most superintendents, more or less willingly, adapted to the role of manager of a custodial warehouse, some did speak out and, by the 1860s, had eminent supporters in such men as John Charles Bucknill, Lockhart Robertson, Henry Maudsley, Joseph Mortimer Granville, John Arlidge and Andrew Wynter. Many of them questioned the value of the whole asylum system, as it had now become, and argued in favour of letting the insane rather remain at home or be boarded out in private houses where they could continue to experience the ordinary life that was now so far removed from the daily routines of the asylums. Often they were prepared to overturn their own earlier arguments in support of asylum care, saying that experience of the

new system had shown them the error of their previous thinking. In 1871, when Maudsley gave the presidential address to the Medico-Psychological association, he gave it as his view that asylum treatment actually made insanity worse, giving rise to "asylum-made lunatics."

However, there was then little political or public support for such challenges to the asylum system. The public seemed to wish to believe that, overall, the reforms had worked well, removing the worst abuse, and showed little desire to have the insane returned to the community. The very large amounts of money only recently invested in the new system provided a great institutionalised inertia to block any calls for more change. Public fears of insanity, fuelled by a series of stories about homicidal maniacs, swung opinion behind calls to protect the public rather than to cure the sick.

2.4.5 More views on madness and continuing tensions and confusion

The years 1845-1900 witnessed more changes in ideas about the nature of madness that inevitably affected ideas on the best ways to deal with it.

In 1845 John Conolly, who was one of the original champions of moral treatment, had argued that insanity was an illness that could affect anyone, like any other illness. It required medical supervision but could, if caught in its early and acute phase, offer good hope of a cure.

However, by the 1870s, when Maudsley was promoting his views, the social, political and economic backdrop was very different and his views both helped form and were formed by this context. It was a time of economic depression and high unemployment. The threat of riots and class revolution seemed very real and the work of men like Charles Booth seemed to point to the existence of a menacing underclass. When Maudsley spoke, the asylums had grown to be vast warehouses containing 1,000-2,000 patients. [The total population of England was then 23 million and many towns had only 4,000 residents.] The concept of madness had also broadened to embrace a much wider range of symptoms and behaviours. There were widespread fears of an epidemic of madness that might overturn the social order: an editorial in "The Times" in April 1877 read:

> if lunacy continues to increase as at present, the insane will be in the majority and, freeing themselves, will put the sane in asylums (Scull 1979).

It was a golden age for faith in scientific answers to a host of problems. Medical work in other areas encouraged the belief that there might be a

physical cause for insanity that would be discovered through the rigorous application of scientific methods rather than through the provision of a therapeutic environment. There was an intellectual climate that favoured record keeping and classification. When this was coupled with Darwin's work on the laws of selection and survival, the idea took root that there might be a hereditary disposition to madness and that the insane were therefore congenitally inferior to the sane. Daniel Tuke, writing in 1878, described the perception of the insane as,

> an infirm type of humanity....on admission "No Good" is plainly inscribed on their foreheads (Scull 1993).

From approximately 1870 to 1915 a Darwinian model of determinist psychiatry was the dominant one, viewing insanity as an evolutionary reversal, a regression to a lower nature. The poor and disreputable were thus a breeding ground for a madness that could not be cured but must be segregated and eradicated as far as possible. Even those who appeared cured should not, on this interpretation, be discharged back into the community, because there they might reproduce and pass on their hereditary predisposition to mental weakness.

Thus it was that, having been subsumed into the medical sphere in the earlier part of the century, the latest scientific and medical ideas now contributed to the development of a custodial, rather than curative, asylum system. The only major piece of lunacy legislation in this period, the 1890 Lunacy Act, reflected this, being concerned not with calls for reform of the system but with protecting the right to liberty of those outside it by tightening up the safeguards against wrongful committal. A custodial asylum with powers of detention, little hope of a discharge as cured and operating within the philosophy and practice of the poor law was obviously no place to find oneself unnecessarily.

Barham has written:

> To a considerable extent the history of the Victorian asylum reveals the victory of custodial realities over rehabilitative good intentions. Contrary to the intentions of the early Victorian reformers, the Victorian asylums became gigantic warehouses for the chronically insane (Barham 1992).

Some of the reasons for this have already been examined in this chapter. All are rooted in the continuing ambiguity and uncertainty about the nature of insanity and about the kind of relationship with the insane that society wished to promote. The very physical appearance of the asylums reflected

these tensions: their imposing facades and surrounding palatial grounds giving way to dark, low and prison-like interiors whose fabric was crumbling [cf. descriptions of Colney Hatch 1857 (Showalter 1987)].

Equally duplicitous was what went on within those buildings, which revealed the clash between the theory and practice of asylum management, the yawning reality gap between an asylum's image of itself as projected in its published reports and minutes and the actual daily reality of life on the wards as revealed through cases such as that at the Lancaster Asylum in 1870.

There was a constant clash between the asylum managers' desire for order and the essential disorder of insanity. Scull sums up the problem for the new profession of mad-doctors:

> In practice the definition of actions as symptoms could not be maintained if the institution was to continue to function, and yet could scarcely be discarded if the asylum doctors were to continue to maintain the fiction that their work was essentially medical in character (Scull 1993).

The complex pattern of opposing forces that influenced the development of the asylums over this period brought about the remarkable changes outlined in this chapter, which completed the dominance of the view of the insane as essentially "Other" and left little remaining scope for the development of therapeutic institutions for them.

2.5 Mid-life crisis: 1890–1930

Thus it was that the typical lunatic asylum in 1890 was a large, custodial and highly regimented long-stay institution, its inmates mostly poor, middle aged and suffering from severe and chronic conditions. It was also the only place and type of treatment for insanity available to most people. Henry Maudsley had described the asylums as "vast receptacles for the concealment and safe keeping of lunacy" (Scull 1993). This remained an accurate account of their role for many decades and into the twentieth century.

In keeping with this, the 1890 Lunacy Act had concentrated on the legal aspects of insanity and of confinement within an asylum. However, by 1930, when the next major piece of mental health legislation, the Mental Treatment Act was passed, great political, social and economic changes had taken place within British society that helped to reshape and reposition the asylum once more in line with the reformers' original vision of it as a place for the treatment of early and acute cases of madness. In 1926 the Royal Commission

on Lunacy and Mental Disorder [known as the MacMillan Commission] published a report stating that "the keynote of the past has been detention. The keynote of the future should be prevention and treatment" (Busfield 1986). Following on from this, the 1930 Act concentrated on the medical aspects of mental illness, looked at the possibilities for a wider range of services for it, offered in a variety of locations and made official a whole new vocabulary of madness–now mental illness.

This section will examine the events and influences of the intervening years that helped to bring about such changes in ideas about the nature of mental illness and of the best ways of dealing with it.

2.5.1 The problems caused by chronic cases and certification procedures

There were two immediate and very practical obstacles in the way of transforming custodial asylums into hospitals. They were to find alternative methods of care for those with chronic and incurable conditions and to find ways to encourage people to come forward for treatment at an early stage. These twin problems were repeatedly addressed during this period and a variety of solutions proposed, such as the boarding out of chronic cases or the establishment of separate institutions for them as well as changes to admission procedures. The reformer, Joseph Granville, suggested that certification should take place after, rather than before admission, or even that some cases could be admitted without any certification. However, public fears of both wrongful confinement and of madmen on the loose made such changes a very sensitive area that politicians were unwilling to take on board. Consequently these changes came about only gradually and within the private sector.

In 1907, Henry Maudsley tried to carry out his ideas for reform by donating enough money to establish a new mental hospital in London especially for early and acute cases, which people could attend as either in- or out-patients and without any certification. This hospital opened in 1915 and thus, in fact, dealt mainly with cases of shell shocked soldiers from the First World War.

It was the large numbers of such "war neuroses" that led to the establishment of new psychiatric clinics attached to general hospitals and offering the new treatments of hypnosis, catharsis and analysis. However, resistance to any general change in certification remained strong and the first attempts at securing reform, in 1915 and 1922, did not succeed.

In 1921 Dr. Montague Lomax published a book detailing his experiences as an asylum doctor. This prompted such outrage that a Royal Commission, led by H.P. MacMillan, was established to investigate the current state of

provision.

2.5.2 The effects of the rise of office psychiatry and of changes to the Poor Law

Many of the influences and examples that helped to bring about the changed emphasis of the 1930 Act came from developments in psychiatry outside the asylums and from the gradual breakdown of the existing poor law system.

This period witnessed rapid growth in the numbers of psychiatric doctors who set up private practices for treating the less severe disorders, for which the public asylums made little provision. They made use of, and developed, treatments such as mesmerism, hypnotism, the rest cure and psychoanalysis. G.M. Beard's work on the concept of neurasthenia and its effects on business and professional people, had helped to give legitimacy to these types of mental disorder. Gradually such treatments came to gain respectability and this encouraged more people to seek medical help for a wider range of mental problems.

At the same time, Freud's work was directing interest and attention on to the internal and psychological, rather than just the physiological, origins of mental disorders. This challenged current thinking on the nature of mental illness and of the best ways of treating it. He also argued that there is a continuum of mental functioning, so challenging the orthodoxy that there is a clear dividing line between health and disease, the sane and the mad, those in the community and those in the asylum.

A major factor contributing to both the genesis and acceptance of the ideas expressed in the 1926 Report from the Royal Commission and in the 1930 Act was the change simultaneously taking place with regard to the poor law. The proposals put forward by the MacMillan Commission ran completely counter to the philosophy of the Victorian poor law, with its emphasis on deterrence, low expenditure, institutional care and itself as the sole provider of welfare benefit. Consequently it is unlikely that the new ideas on mental illness would have been accepted, or promulgated, without the changes that took place under the Liberal government from 1906-1911. The work of its Poor Law Commission from 1905-1909, plus the introduction of pension schemes in 1908 and the 1911 National Insurance Act, all contributed to forming a different conceptual framework for welfare provision, since they showed that public benefits could be provided outside the old poor law system, thus undermining its core values of institutional deterrence and benefit as a last resort.

The following decade saw the gradual, but continuing, broadening of wel-

fare provision outside that system. Furthermore, in 1919 the government established the first Ministry of Health which, in 1920, took over the powers over lunacy and mental deficiency which had, until then, been vested in the Home Office. This marked a very important change, both symbolically and practically, for the future of mental health services. It showed the official view now to be that madness was mental illness; primarily a disease like other, physical diseases rather than a matter of public order, requiring control and deterrence.

During this period, the large numbers of soldiers suffering from shell shock also influenced people's feelings about provision for mental disorders. When so many respectable men were afflicted in the service of their country, they undermined the old arguments about the type of people who suffered in this way and the custodial lunatic asylum seemed no fitting place for them. Therefore public support grew for the development of some other type of publicly funded provision outside its grim physical walls and spaces and outside the grim moral, social and economic spaces of both the asylum and the poor law.

The return of a Labour government in 1929 and its ensuing poor law reforms set the final stone in place for the successful passing of the 1930 Act.

2.5.3 The Royal Commission on Lunacy and Mental Disorder [1924-6] and the 1930 Mental Treatment Act

When the Royal Commission's report was published, it took the view that there was a close similarity between mental and physical illness, saying, in paragraph 38,

> it has become increasingly evident to us that there is no clear line of demarcation between mental illness and physical illness (Jones 1993).

Such a statement struck at the very heart of the existing, segregative system. Furthermore, the report again emphasised the need for voluntary treatment, whenever possible, recognising the certification procedures as a major obstacle to successful treatment, and urged that the lunacy system be completely separated from the poor law. This would release the asylums from their role as a custodial place of last resort for paupers.

The 1930 Act accepted some, but not all of the Commission's recommendations. In particular it made allowance for three categories of admission to

an asylum; voluntary, temporary [up to six months], and certified. It also allowed local authorities to provide out-patient and after care. Although most authorities were slow to take up these powers, their introduction nevertheless marked a new stage in the disintegration of the asylum's monopoly as the sole location for state-funded treatment of mental disorders.

The Act also introduced important changes in terminology: the asylum became the mental hospital; the lunatic became a person of unsound mind, or a patient; a pauper became a rate-aided person; an attendant became a nurse (Busfield 1986). These changes in vocabulary marked the wider change taking place as the existing, largely legal, concept of insanity transmogrified into the largely medical concept of mental illness; i.e. the conceptual framework which has been the basis for the provision of mental health services for most of this century. Indeed Prior, in his study of the social organisation of mental illness, claims that:

> from 1930 until the 1970s this new vocabulary provided the essential building blocks of psychiatric practice (Prior 1993).

And so the pronouncements of the 1930 Act set the tone for the development of mental health services over the ensuing decades. These were to witness another upsurge of therapeutic optimism and so see psychiatry more firmly rooted within the realms of general medicine. This was demonstrated in the 1940s when the National Health Service was established and, despite some dispute, included mental health services within its remit.

However, confusion about, and unhappiness with, the role of the asylum, now the mental hospital, continued, with constant pressure for a wider range of treatment options, delivered in a wider range of locations and for a more open style of asylum management. The boundary between the asylum and the community was increasingly under attack.

The buildings and services that any government and society provide for mental illness tell us a great deal about that society, as well as about its views on the nature and causation of mental illness. The differing emphases of the 1890 and the 1930 legislation reflect wider cultural changes during this period, not simply changes within psychiatry itself. By 1930 madness was again viewed as a medical problem and, at least in theory, susceptible to treatment and cure. However, the difference from the views held about it one hundred years previously, was that now there was no longer felt to be a clear boundary between sanity and madness, nor between physical and mental illness. It was this that marked the beginning of the end of the asylum. However, whether it also marked the beginning of the end of the view of people suffering from mental illness as the "Other" remains much more doubtful.

2.6 A lingering end? 1930–1960

Joan Busfield, in her study of mental health policy and practice, has described the 1930 Act as having "laid the foundations for the pattern of mental health services in the second half of the twentieth century" (Busfield 1986). The reasons why the Act gave expression to these views and why they have been developed and continue to be dominant, lie in a complex net of interrelationships between the medical professions, lay opinion, the State and economic and cultural pressures. The views expressed in the Act were not, in themselves, new, nor did they appear unexpectedly and were then imposed upon an unwilling public. Rather the time was then ripe for their acceptance, since they built upon continuing debates around the definition, causation and organisation of madness, caused by and set within the wider cultural backdrop.

2.6.1 Therapeutic optimism again; the medical model and the concurrent weakening of the custodial role

The discovery in 1917 of the specific aetiology of general paralysis of the insane [GPI] gave added impetus to a fresh wave of therapeutic optimism with regard to mental illness and thus furthered the dominance of the medical model of madness. Once the cause of GPI was shown to be syphilitic micro-organisms, the idea that all mental disorders might have some similar origin gained favour. This sat well with the wider medical model of the times, which was dominated by germ theory and laboratory medicine, as illustrated in the work of Kraepelin and Bleuler on dementia praecox/ schizophrenia (Jones 1993). These successes fuelled a willingness to fund work on a range of new physical treatments. 1936 saw the first use in Britain of insulin coma therapy, followed by the introduction of electro-convulsive therapy [ECT] in 1937 and various forms of psychosurgery from 1941 onwards.

Although these developments had huge effects upon the inmates of the mental hospitals, who acted as the guinea pigs for each successive treatment, they had little impact on the outward form of the services. Mental hospitals began to include within their design space for surgery suites or hydrotherapy pools, but these posed no challenge to the hospital as the most suitable locus of this medical care.

Writing about any period of asylum history is difficult because of the tensions that were always present within its role: what Barham calls, "its essentially duplicitous nature" (Barham 1992). It is always hard to give

adequate emphasis to both the vision and the reality of asylum life, especially as there often was no one coherent and dominant vision. Christine McCourt-Perring, writing of psychiatric hospital closure, says:

> changes in ideas about care are not as coherent as they might seem, and contradictions within such broad ideologies have often mitigated against change in policy and practice (McCourt Perring 1993).

The problem is especially acute for this period, which saw the coming to crisis point of the asylum's attempts to reconcile its dual roles of care and custody, of hospital and dumping ground.

In many ways the asylum did transform into the mental hospital in the 1930s, and yet it still contained a large percentage of chronic and long stay patients who were compulsorily detained there. Very few local authorities took up the opportunity to provide out-patient and after care facilities elsewhere and so the asylums retained much of their custodial character and warehousing role and in-patient numbers continued to rise.

Yet, with the official emphasis once again on treatment and cure, these custodial features did come to seem increasingly inappropriate. From the 1920s onwards some asylums began to introduce more open systems, with some wards becoming unlocked and some patients allowed out into the grounds, or even into the local community, unattended. During the 1930s and 40s these practices became more widespread, until Dingleton Hospital, in Scotland, became, in 1949, the first to extend it to cover the whole hospital. In this way the hospitals became gradually less prison-like and started to develop links into their local communities.

2.6.2 Critiques of hospital based provision; the social model and the development of therapeutic communities

As the latest medical model of the causation, treatment and cure of mental illness sought to establish its dominance, there continued to be, as there always had been since 1800, dissenting voices, and a strong body of criticism of the very idea of institutional care for the mentally ill was developing. The critics did not, however, have a shared vision but rather their concerns covered a range of issues and possible solutions.

Adolf Meyer [1866-1950] and H.S.Sullivan [1892-1949] supported the view that there were social origins to psychiatric disorders and the term "social psychiatry" was first used in 1917 to describe the work of Southard (Prior

1993). If there were social causes, then making the sufferers withdraw to isolated and enclosed institutions would not be an appropriate way to tackle the problem. This concern was repeatedly voiced in journals, reports and surveys, fuelling much criticism, by the 1930s, of the idea that mental hospitals could provide a therapeutic environment for the mentally ill. These criticisms focused attention back onto the long-stay patients, who could become what Maudsley had several decades earlier described as "asylum-made lunatics" through the adverse effects of spending many years inside an asylum; a process that came to be known as institutionalisation or institutional neurosis (Barham 1992). The critics argued that more active treatment programmes and better physical and social environments needed to be provided within the hospitals and more contact developed with the local communities. Thus they contributed to the adoption of the open-door policies described above.

At the same time, a number of social surveys were being undertaken, part of a wider desire for social measuring, recording and counting of all kinds. In the 1930s Faris and Dunham had looked in detail at mental disorder in different zones of Chicago (Faris & Dunham 1939). Their work exerted an important influence upon later work in England looking at the connections between social class and mental illness. These surveys revealed the widespread prevalence, and later also incidence, of mental illness amongst people living in the community, and the ways in which community life could itself contribute to its causation. By showing that many people with quite severe psychotic disorders were nevertheless managing to survive in the community, such surveys further demonstrated that the asylum wall was not an effective boundary for "the containing and safe-keeping of madness"; and that there could be alternatives to institutional life, even for those with severe problems. Since the very concept of mental illness had to be operationalised before it could be measured, the methodology of these surveys also drew attention to the problematic nature of the definition and recognition of mental illness. This opened up a space for those who wished to develop their view of mental illness as socially constructed to challenge the current pattern of mental health services.

During the 1940s and 50s, under the influences outlined above, the open-door policy gained ground and some hospitals began to set up therapeutic communities within their grounds; on the margins between hospital and community, as it were.

The pioneering work on such communities was undertaken by Tom Main at Northfield Military Hospital in the USA, as part of his work rehabilitating soldiers and civilians who were suffering as a result of the traumas of the Second World War. Main described the aim of his experiment with these

communities as being:

> an attempt to use a hospital not as an organisation run by doctors in the interests of their own greater technical efficiency, but as a community with the immediate aim of the full participation of all its members in its daily life (Prior 1993).

This idea, of using the community-like qualities of hospital life as a therapeutic tool, provided one way of answering the criticism of the adverse effects of hospital life.

Main's work was also building on the earlier social surveys, which were now being employed within hospitals and revealing the nature of hospital communities and the daily structure of patients' lives. A study carried out by Stanton and Schwartz at Maryland Hospital (Stanton & Schwartz 1954) was particularly influential in this respect, for it had shown both that treatment outcomes could be linked to patients' social circumstances and that hospitals were themselves social systems.

In the UK these ideas were taken up by Maxwell Jones, who established the first therapeutic community at Dingleton Hospital in 1962. In a setting reminiscent of Tuke's moral treatment, he placed the patients in separate units of no more than one hundred, where staff and patients tried to break down the traditional, medical power structures and instead work together to bring about a cure within a supportive and more "normal" environment.

Although very few such communities were established, they nevertheless demonstrated the direction in which even mainstream ideas on the nature and treatment of mental illness were now moving and the growing interest in its social aspects. They posed a challenge to the biomedical model and fed the continuing criticism of hospital based care which was soon to reach its peak in the works of Goffman, Szasz and Laing.

2.6.3 Developments in psychiatry and the NHS

Despite these challenges, this period also saw many developments within the medical model. The impact of the Second World War on social thought and the development of state health and welfare provision had profound effects on mental health services (McCourt Perring 1993). When the NHS was established, despite some opposition, it included mental health services, which served to integrate them more closely with the other health services and to underline support for the medical model. Parliament had again, as in 1930, accepted the argument that there are essential similarities between physical and mental health problems. Psychiatrists, as a professional group, were strong advocates of this and the consequent tightening of the links between

psychiatry and the other branches of medicine undoubtedly improved their status and helped to desegregate them, if not their patients (Busfield 1986).

The NHS Act made provision for the establishment of psychiatric units at District General Hospitals, as part of this integration, and for the provision of a broad range of services for a broad range of clients; a very different model from that of only segregated hospital services for the severely ill. But, at the same time, the role of local authorities in providing welfare services outside hospital remained voluntary. Therefore funding for services such as residential homes and social work support for after care was always vulnerable and gave rise to considerable variation in practice around the country.

The role of voluntary organisations concerned with mental health was also developing during this period. They began to both provide alternative, community based services and to campaign for improvements in hospital provision.

Despite these developments, in-patient numbers continued to rise, reaching their peak at 148,000 in 1954.

2.6.4 The introduction of psychotropic drugs and the continuing debate on the nature of madness

The search for, and introduction of, new physical treatments continued apace into the 1950s, when new psychotropic drugs were introduced: another interventionist treatment, aimed at the body as the cause of the problem. These chemical methods rapidly came to dominate psychiatric treatment. Chlorpromazine and Reserpine were introduced in Britain in 1953, followed by the use of lithium salts in 1956. Initially they were used to calm patients and thus make them more easily managed in overcrowded and understaffed wards. More detailed technical arguments in support of their therapeutic powers appeared only many years later (Prior 1993). Thus the medical model remained strong. Writing about the continuing dominance of this view of madness, Prior says:

> despite their radically altered physiological and chemical images, body and brain, as fields of action and objects of study, are as central to the psychiatry of the late twentieth century as they were to the psychiatry of the first two decades of this century (Prior 1993).

Although this view of mental illness remained very powerful, it was still not without challenge. The work of Freud and his followers continued to highlight the psychological factors and psychodynamic features of mental

disorder. Meyer and his followers emphasised the importance of seeing the patient within his/her social context. Meyer had made careful studies of his patients' lifestyles and reactions to their surroundings, leading to his typology of mental illnesses as "reaction types". Maxwell Jones was likewise trying to demonstrate the importance of social factors in his therapeutic communities (Jones 1952). R.D. Laing's book, "The Divided Self" (Laing 1959), was published in 1959. It also placed much emphasis on patients' social networks and their effects upon the functioning of the self. 1959 also saw the first reports of Eysenck's work on behaviour therapy.

The cumulative effect of this was to gradually make a patient's social relationships and social life a respectable object of psychiatric study, since they were, arguably, part of the aetiology of mental illness. The 1950s witnessed a crumbling of some of the old "certainties" about the nature of madness and where it both was and should be. Although the mental hospitals retained their central role, they now had alongside them a range of other practices and facilities and a growing feeling that mental illness could not be adequately tackled on a site isolated from wider social and community life.

2.6.5 The Percy Report [1957] and the 1959 Mental Treatment Act

Against this backdrop, a Royal Commission was established in 1954 to look at the law relating to mental illness and mental deficiency. Its report, published in 1957, and known as the Percy Report after the commission's chairman, has been described as:

> the turning point in official policy concerning mental health services, from a hospital to a community based system of care and therapy (Busfield 1986).

The Commission had been established, at least in part, because of the anomalies and confusions that had arisen from the inclusion of mental health services within the NHS. Its report continued to support the view that, "disorders of the mind are illnesses which need medical treatment"; that the use of compulsory admission and treatment should be as limited as possible; and that these decisions should be taken by the medical profession alone, without the need for a magistrate's order. This constituted a complete overturning of the 1890 Act in both practice and philosophy. The report recognised that the term, "mental illness", covered a wide range of conditions and needed a correspondingly wide range of treatments and facilities, not necessarily including an in-patient stay. Overall the report recommended a shift from

hospital care to community care and, "integration into the community rather than separation from it had become the new ideal" (Busfield 1986).

In this context of a time when the state was playing an increasing role in the provision of health and welfare services and voluntary organisations, campaigning on behalf of people with mental health needs, were becoming more vocal and powerful; when the medical model of mental illness, although challenged, remained the dominant one, depicting mental illnesses as being similar to physical ones and treatable outside an asylum, the Percy Report was largely accepted and formed the basis for the 1959 Mental Health Act.

This Act reaffirmed the medical model and called for a substantial expansion of community based services on the grounds that these could provide better and more appropriate care. Following in the footsteps of the 1930 Act, it further relaxed the legislative framework for admission to and discharge from in-patient care and foresaw a large reduction in hospital based services contemporaneously with the growth of community based local authority services, such as hostels, day care, social work support and sheltered employment schemes. Fatally, however, this vision was not given legislative or financial backing (Means & Smith 1994). Through this failure, the years 1962 -1990 came to be described by one commentator as, "disaster years for people with mental health problems", because they marked a period committed to scaling down the existing provision but not able, or willing, to provide an adequate alternative (Murphy 1991).

The Act, by giving official voice to this model of mental illness and the best spaces for its treatment, laid the ground for Enoch Powell's speech, as Minister of Health, in 1961 predicting a fifty percent reduction in in-patient beds within fifteen years and the eventual disappearance of the long stay hospital population; a vision reiterated in the 1962 National Hospitals Plan and in the 1963 Community Care plan. Taken together these seemed to sound the death knell for the lunatic asylum.

2.7 Conclusion

This chapter has traced the life history of the lunatic asylum from its troubled and torn beginnings in the early years of the nineteenth century through to the start of its equally troubled demise in the 1960s. This was a period which witnessed many dramatic changes in the asylum's role and function, starting, under the terms of the 1845 Lunacy act, with the move from unregulated, ad hoc, local provision for the insane to the establishment of a nationwide , publicly funded, asylum system, which was centralised and highly managed and gave legitimacy to the segregation of the insane on the back of a wave of

therapeutic optimism, situated within a changing society that no longer felt that it had a place for such people.

The 1845 Act marked the passing of control over the management of the mad from lay people into the hands of medical practitioners and, by establishing madness as mental illness and setting up a national system of asylums, it provided the ideal locus for the development of the medical speciality of psychiatry.

However the vision of small, therapeutic asylums based on moral management rapidly materialised rather as large scale, custodial and highly regimented institutions for the incurable, on the back of a wave of therapeutic pessimism, situated within a society that had convinced itself that large was better, in terms of asylum care for the insane. For the early asylums soon filled up with chronic cases. As they grew larger and larger to accommodate the ever increasing numbers of the insane so their management styles and staff roles had to change accordingly, under the influence of the increasingly complex rules and regulations necessary to manage these much larger institutions. In any case the asylum's perilous situation, pitched as it was against the quite contrary concerns and philosophy of both the poor law and the legal system, would always have made it difficult to maintain the reformers' early visions.

By the time of the next piece of lunacy legislation, the 1890 Lunacy Act, the rapid growth of the asylums had contributed to public fears of an epidemic of madness threatening to overturn the established social order. Consequently that Act was firmly set within a legalistic framework concerned only with control and public safety, whilst developments in other areas had fuelled the view of the mad as a lower type of humanity prone to a terrible, hereditary and incurable disease.

However, by 1930, when the next piece of lunacy legislation, the 1930 Mental Treatment Act, was passed, therapeutic optimism had revived, alongside changing attitudes to madness, giving rise to a reversal back to earlier emphases upon prevention and treatment and stressing the medical, rather than legal, aspects of madness. In response to such things as the rise of office psychiatry, with its support for the psychological aspects of mental distress, the horrific suffering caused by the World War, for which the custodial asylums seemed no fitting setting, and the breakdown of the old poor law to be replaced by a new conceptual framework for welfare provision, this Act marked a watershed in official thinking about mental disorder. It depicted it as mental illness, a medical concept, and no longer so clearly differentiated from either physical illnesses or from sanity. Furthermore it made allowance for local authorities to establish locations other than asylums for its voluntary treatment. Such changes, even if only rhetorical, in turn helped to ensure

that mental illnesses were included within the National Health Service.

However, changes in policy and practice seemed slow to follow, and so the consequent years witnessed continuing confusion about, and unhappiness with, the role of the asylum/ mental hospital. Given the understandable reluctance of local authorities, given the other pressing and statutory requirements upon them, to develop any alternative, the mental hospitals continued to be plagued by their twin imperatives of both care and custody. Only gradually did other sites for, and approaches to, mental illness gain ground, not only geographically but also ideologically.

Nevertheless, by 1959, when the Percy Report was published and incorporated into the 1959 Mental Health Act, the official view was that treatment for mental illnesses was both better and more appropriate if provided in community settings. This Act provided for the scaling down of the existing, separate mental hospital provision but still failed to enforce the development of the desired alternative to it. It was the gradual disappearance of the old asylum from the geographical, political and moral landscape that then became the goal of government mental health policy as the cycle of arguments and debate about mental illness rolled inexorably on, for, beneath these dramatic surface changes to the asylum, some things remained constant.

The nature of mental illness and its best treatment were always debated and challenged, as were the motives of those formulating its policy and practice [as, indeed, they continue to be to this day]. There have always been competing models, broadly defined as a medical model, which sees madness as a medical category with a biological basis, and a social model, which lays greater emphasis on the importance of people's environment. Although the medical model can, and increasingly has, incorporated an acknowledgment of the contribution of social and environmental factors in the aetiology of "mental illness", there continues to be an oppositional social model which sees "mental illness" as a socially created and constructed category.

There have always been scandals about the parlous state of the existing provision. That provision has, itself, never arisen or functioned simply as a rational response to intellectual debates but has always had to form a compromise between such thinking and a whole host of other competing social, political and economic pressures. The asylum's development was always subject to a complex web of, often opposing, internal and external forces.

In the 1870s, Andrew Wynter, a contemporary reviewer of the new system of publicly funded asylums felt able to declare:

> the county asylum is the most blessed manifestation of true civilisation the world can present (Scull 1979).

One hundred and fifty years later, few commentators would echo such

unbridled optimism, viewing the establishment of the asylums and their concomitant legacy for people with mental health needs as being far more ambiguous and problematical. Peter Barham for example, in his opening chapter says:

> if asylums are typical products of modern societies, so also are the alarms and scandals that have arisen around them. The asylum has always been a problematic and unpredictable creation and has never settled placidly into the social landscape for any length of time (Barham 1992).

He sees the main legacy of the Victorian asylums as being the view of those with mental health needs as essentially "other" than the rest of society and hence the transformation of people suffering with mental illnesses into mental patients permanently exiled to the margins of society.

Simple, linear descriptions of the birth of the asylum as part of man's progressive humanitarianism and enlightened response, or indeed its opposite, no longer seem convincing in our own times. It would seem, rather, that the roots and development of the asylum must be sought in a complex pattern of influences and desires, some contradictory, some not even openly acknowledged. Busfield, in her concluding chapter, claims:

> contemporary mental health services and psychiatric ideas and practices have been moulded and fashioned by the complex interplay of two interrelated, but often opposing, spheres of influence (Busfield 1986).

She defines these as, broadly, those of medicine and of the state.

Scull (Scull 1993) too sees a complex beginning to the asylum era, rooted in a society struggling with problems around the nature and treatment of mental illness, the "moral and epistemological uncertainties around mental health" that are still unresolved today (Rogers & Pilgrim 1996).

This chapter has shown that it was never clear for whom the asylums were provided. Although the debate was conducted in terms of whether or not they provided the best spaces for people with mental illnesses, the voices heard in that debate were those of politicians, mental health professionals and the public. These people each had their own, competing conceptualisations of mental illness and their own, competing concerns about the response to it. Lay people may associate mental illness with threats of violence to themselves and so seek from politicians a response that will offer them protection against this perceived threat. Mental health professionals may have developed different ideas on the nature of mental illness and be seeking from

politicians a response which will enable them to develop their therapeutic ideas and/ or which will provide comfortable jobs for themselves. Politicians have their own political targets and concerns to address. Patients' own conceptualisations of their experience and their views on the best response to it [which may have been different again from those of politicians, professionals or the public] were rarely heard directly and had no power to shape the resulting definitions of mental illness or the spaces provided for it.

Consequently the physical, social and moral "shape" of the asylum continued to change in response to this wider debate but it was able to assimilate the various challenges, developments and conflicting demands within a continuing medical and hospital focus and without any radical break. Even in its death throes in the latter part of the twentieth century the problematic asylum has continued to exert massive influence over the fledgling community care services struggling to develop in its shadow. The debate as to whether that shadow was cast by a caring refuge providing shelter and treatment or by a dumping ground providing only a hopeless incarceration was to continue for many more years and to become yet more confusing, as discussed in the following chapter, as the mental health services found themselves caught up in wider debates about the possible shapes, locations and functions of community care for people with physical and sensory impairments, older people, and people with learning difficulties, as well as those with mental health problems.

> *" Now this is not the end, It is not even the beginning of the end,*
> *But it is, perhaps, the end of the beginning. "*

Speech, 30th December 1941, Sir Winston Churchill.

3. THE MYSTERY OF THE MISSING COMMUNITY CARE: MENTAL HEALTH SERVICES, 1930 -1990

3.1 Introduction

Mental health services in England have, since the 1950s, been part of the group of services known as the "Cinderella services" but those wanting to tell, or listen to, the ever unfolding story of their development must question what they say or hear and ask about this Cinderella's background and family history and the wider social setting in which she lived.

The previous chapter has given an account of the changing shapes and spaces provided by the lunatic asylum/ mental hospital between 1800 and 1960, particularly for people with mental health problems and has highlighted the difficulties experienced during that time because of the unresolved tensions and dilemmas contained within mental health policy.

This chapter will focus on the policy change to community based treatment and care for people with mental health problems. Because the early chapters of this thesis adopt a thematic rather than strictly chronological structure, this chapter covers some of the same years as the previous one, but with a different emphasis. It examines the equally confused and confusing tale of the mental health services from 1930 until 1990, and their continued failure to "go to the Ball", if that is what it is, of community care. If it was hard to be sure what "spaces" asylums provided, community care "spaces", devised as they are for a range of client groups, are even more difficult to find.

In her Reith Lectures, Marina Warner described myths as "a kind of story, told in public, which people tell one another. They wear an air of ancient wisdom, but that is part of their seductive charm" (Warner 1994). In that case, the tale of the mental health services during this period has mythical elements; sources both of hope and fear. For myths are not fixed,

but are always being retold and thus becoming new tales. The modern myths of madness, told and retold, often reveal as much about the nature of late twentieth century British society and the way we would like life to be as they do about the nature of mental illness and the best way of providing for it.

The provision of a community based model of treatment and care has been official government policy for the past forty years and came, during that time, to be almost universally hailed as a desirable objective, not only in the UK but also in most other Western countries (Goodwin 1997). Over this period, the value of institutional forms of care has been heavily criticised and derided and its dangers highlighted, whilst the value of community based services has been lauded and enthusiastically argued for, until, as in Animal Farm, the old mantra was overturned and "Any asylum is better than the community" became, "Any community is better than the asylum": the relative merits of the two models of care came to be regarded as almost self-evident truths, no longer really open for debate.

Despite this continuing official enthusiasm, it seemed that no-one could wave the magic wand to make the change take place until the late 1980s, by which time these truths were starting to seem not so self-evident after all and the stage was set for Virginia Bottomley, then Secretary of State for Health, to declare that, in the context of the mental health services' move from institutional to community based models, "the pendulum has swung too far."

All the people who took part in the interviews for this study had experience of using community mental health services and were aware of the continuing public debate about them. The history of the rise of such services has had a crucial effect upon their lives and experiences, for they were the people who found themselves caught up in the stormy waters of the local resettlement programme set against a national backdrop of the concerns raised by a series of high-profile killings committed by people with severe mental health needs living in the community. Indeed their own community had been the setting for one such murder. They were all too aware of the backlash setting in against a community care that had, in their area, barely begun to develop.

3.2 Cinderella's family background

As discussed in the previous chapter, the 1930 Mental Treatment Act laid the foundations for the mental health services in this century by its emphasis on a medical view of madness, with no clear line of demarcation between mental and physical illness. It reflected a new wave of therapeutic optimism around

the causation and treatment of mental illness that focused on interventionist treatments practised on individual bodies. This viewpoint will form a continuing theme in this tale.

The 1930 Act also made it possible for local authorities to provide outpatient and after-care facilities outside the asylum. Most, however, were reluctant to do so. This separation of treatment and care, and the reluctance, or inability, of local authorities to provide adequate care arrangements is another continuing theme in the tale.

A third theme, and one that continues from the asylums' beginning, is that of criticism of institutional care for madness. Throughout this century such criticism has drawn on, and sometimes been coupled with, sociological studies of communities and social surveys that contributed new ideas to the debate on the causes and nature of mental illness and highlighted the problematic nature of its definition and recognition. However the findings from such studies have never been clear cut and both pro- and anti- institutional ideologies have continued to develop in parallel, each finding favour with different interest groups and at different times.

The interaction of these three themes, as reflected in and formulated by government policy, public and medical opinion, and wider economic and cultural pressures, combined by the 1950s to make the mental hospitals' continuing custodial features seem inappropriate. The establishment of outpatient clinics during the 1920s and 30s had given a locus and legitimacy to non custodial forms of treatment. The rise of social psychiatry in the 1940s, with its emphasis on the role of patients' social relationships and interactions in the causation and experience of mental illness, had seen the opening of the first day centres and day hospitals; more new spaces where re- conceptualised mental illnesses could be treated with a range of therapies administered by "the medico-social team" rather than by the psychiatrist alone. This changed model reflected more general changes in the conceptualisation of disease: no longer merely carried in certain, individual bodies but rather possibly latent in many bodies and developing in some under particular social and environmental circumstances. Indeed Prior claims that, by the 1950s, "the age of the isolated, asocial patient had come to an end" (Prior 1993), although perhaps more in theory than in practice.

Against this conceptual and theoretical background, the development of the open ward system and of therapeutic communities and the greater integration of mental health services with those for physical illness under the terms of the 1946 National Health Service Act, contributed to the crumbling of the asylum wall as a firm boundary between madness and sanity and allowed links to develop between the asylum and the local community. Discussion about the best provision for mental illness in the 1950s came in-

creasingly to involve community and general hospital based services, as was reflected in the findings of the Percy Report [1957] and the subsequent Mental Health Act [1959]. [see Chapter 2, section 5.]

Nevertheless, the tensions always inherent in the asylums' role remained unresolved and were transferred into community care planning. Although a desire to dismantle the asylum system grew from the 1930s to the 1950s, so did the number of in-patient beds, reaching their peak in 1954. However, any clear alternative to asylum provision signally failed to grow in the absence of large-scale funding and legislative backing.

3.3 1961: Could Enoch Powell be the fairy godmother?

The passing of the 1959 Act was clear recognition that the provision of services for people with mental illnesses was a priority area, high on the political agenda. The continuing wave of therapeutic optimism fuelled by the introduction of psychotropic drugs, although perhaps not shared by all, was seized upon by the government to support its argument that many more people would be able to have their symptoms managed without an in-patient stay, or, at the least, would need to be hospitalised for a shorter time (Goodwin 1989). In-patient bed numbers were by now starting to decline, from their peak of 148,000 in 1954 to 136,000 by 1960, giving support to the hope that the long standing problems caused by chronic cases, that had so muddied the ideals of asylum care in the previous century, might at last be solved by their disappearance from the scene.

So it was that Enoch Powell, then Minister of Health, could appear at the National Association of Mental Health's 1961 annual conference and declare, in a typically passionate speech, that the number of in-patient beds would be substantially reduced within the next fifteen years and that the long stay population might well disappear altogether.

> I have intimated to the hospital authorities, who will be producing the constituent elements of the national hospital plan, that in fifteen years' time there may well be needed not more than half as many places in hospitals for mental illness as there are today. Expressed in numerical terms, this would represent a redundancy of no fewer than 75,000 hospital beds.....Now look and see what are the implications of these bold words. They imply nothing less than the elimination of by far the greater part of this country's mental hospitals as they stand today. This is a colossal

> undertaking, not so much in the physical provision which it involves as in the sheer inertia of mind and matter which requires to be overcome. There they stand, isolated, majestic, imperious, brooded over by the gigantic water tower and chimney combined, rising unmistakable and daunting out of the countryside –the asylums which our forefathers built with such immense solidity. Do not for a moment underestimate their power of resistance to our assault (Jones 1993).

The Enoch Powell magic spell, reiterated in the 1962 document, "A Hospital Plan for England and Wales" and in "Health and Welfare: the development of Community Care" the following year, was based upon the ultimate closure of the old mental hospitals, which would be replaced by various community based services and some beds within psychiatric units attached to district general hospitals for acute and short-term treatment. In short, Enoch Powell's community care spell was based on the belief that current psychiatric treatment was effective and it needed to be administered in publicly funded provision outside the asylum (Chapman, Goodwin & Hennelly 1991). In this early phase of community care, and perhaps still in some parts of the health service, treatment in general hospitals or living in residential or nursing homes was seen as part of community care. However, the community based treatment part of the equation, through acute and short term work in district general hospitals, was always much more clearly developed and stated than the community based care part, which lacked any clear rationale or central leadership.

3.3.1 What is community care?

This government "spell" for community care was, therefore, neither clear to, not necessarily shared by, everyone. The problem of defining quite what the community care, which was planned to replace asylum provision, might be was recognised early in its existence. In a speech now described as , "a prophetic warning for the psychiatric services and one that has been amply justified by events" (Wistow 1995*a*). Richard Titmuss outlined the problem on the second day of the same 1961 conference, saying that he had been unable to determine either the origins or the meaning of the term, but that:

> institutional policies, both before and since the Mental Health Act of 1959, have....assumed that someone knows what it means.

He added the warning that:

> if English social history is any guide, confusion has often been the mother of complacency....What some hope will exist, is suddenly thought by many to exist. All kinds of wild and unlovely weeds are changed by statutory magic and comforting appellation into the most attractive and domesticated flowers.

He voiced his concern that there would not be enough community based provision to counterbalance the rundown of hospital provision and called, in vain, for improvements to the training of social workers and doctors to match the new style mental health services and for earmarked funds for local authorities to provide them (Jones 1993).

Despite such concerns and a range of opposition to the policy, the government's view continued to be that this was a progressive policy, since all patients would receive better care in the community than in a long stay hospital; a view being repeated at that time, as various comparative mental health studies have shown, "around the psychiatric globe" (Tomlinson 1991) (Goodwin 1997).

Support for this view seemed to be offered by the research findings from various studies (Barton 1959) (Goffman 1961) (Foucault 1965) detailing the adverse effects of institutional care upon mental health problems and thus overturning earlier arguments in support of the redemptive power of institutions in general and lunatic asylums in particular. There continued to be other research projects (Dunham & Weinberg 1960) (Friedson 1963) (Wing & Brown 1970) whose findings could have been interpreted to support improvements in institutional life, since they also discussed the positive aspects of hospital life and treatments, but these received short shrift in the current cultural climate.

By the late 1960s, the ideas for community care provision had broadened to include services for older people, people with physical and sensory impairments and people with learning disabilities, but without any clarification as to the precise meaning or form that such services might have. Many powerful politicians, psychiatrists and social scientists had, via a multitude of routes, come to the same conclusion, that the old style mental hospitals were no longer a suitable space for the containment and treatment of mental illness, but very few alternative spaces were being developed.

A major barrier to such development was the lack of any organisational way to allow the necessary funding to be transferred even from mental hospitals to psychiatric units at district general hospitals, let alone to local authorities, coupled with the inertia value of the existing investment in buildings, staff and skills. By the time that these problems were addressed, in the 1970s, a changed economic climate meant that such changes in services were

much more difficult to develop: that community care might be an idea whose time had gone.

Therefore, although Enoch Powell uttered the words of the spell to enable the development of community care services for people with mental health needs, he was unable, or unwilling, to make the transformation take place. He had recognised the resistance it would face from the existing provision but also failed because he was never able to make clear what it was that he wished to transform this existing provision into, beyond some General Hospital based treatment. This left the impression that community care was only ever an idea, not a fully thought through policy.

This early episode in the history of the proposed move to community mental health services exhibits a pattern that was to be repeated many times over the ensuing years. Mental health services become a high priority on the political agenda. There are many high flown speeches by senior politicians followed by a flurry of inquiries, committees and documents, but very little change. Eventually this activity peters out without the achievement of the objectives, and mental health services disappear from the political scene until the next scandal reveals the same old problems hiding behind different names and organisational structures.

This episode also repeats a familiar pattern from the past, in that the dominant voices shaping mental health policy and provision continue to be those of politicians and psychiatrists; a powerful alliance able to translate the words of official documents in ways designed to serve their own ends and understandings. Thus the part of Enoch Powell's spell concerned with the rundown of the old hospitals was of interest to both these groups because it contained possibilities for reducing public expenditure on welfare that were attractive to the Conservative politicians of the day and possibilities for the greater integration of psychiatry with the other medical specialities that were attractive to the asylum doctors, now armed with psychotropic drugs. The opportunity to relocate asylum theory and practice within the planned network of district general hospitals was therefore the part of the policy that received attention, rather than that concerned with developing community facilities for ongoing care. As Rogers and Pilgrim have pointed out:

> what Powell's uneven policy prompt seemed to do was to encourage a process of re-institutionalisation from the old to the new hospitals, not community care (Rogers & Pilgrim 1996).

Whilst this may well have suited the interests of politicians and psychiatrists, it had some disastrous consequences for patients. The old hospitals had provided custody, treatment and care. The new hospital sites provided

some custody, more treatment and less care. The inclusion of psychiatry, especially as a minor player, within the realms of general medicine meant that there were powerful incentives for it to develop treatments and practices that were a good fit within that wider medical model but not necessarily a good fit with the particular needs of their patients. The dominant, although not only, model of mental illness was set to continue to be the medical one, and not only in the UK.

> Across the whole of Western Europe and North America through the middle part of the twentieth century the medical model of mental health problems was thoroughly absorbed and institutionalised within the practices of psychiatric treatment (Goodwin 1997).

For people living with severe mental illness this both left their ongoing and broader needs unaddressed and provided them with a perverse incentive to be, or appear to be, as ill as possible in order to get the attention which they felt themselves to need.

3.4 The 1970s; slow progress towards an uncertain goal

Any attempt to chart the move to community care is as difficult and complex as attempts to chart the history of the asylum, and for the same reasons. [see Chapter 2. section 5.] The nature of mental illness and the best response to it was still a contested area, the experiences of those who suffered from it were still excluded from the debate and there was no clear and agreed view as to the relationships that could and should exist between people with mental health needs and wider society. In the case of the move to community care, this was further obfuscated by the fact that there was no one movement, but several competing ones gathered around a term whose meaning remained open to a variety of interpretations as the years went by.

The Labour government, under the leadership of Harold Wilson, established a committee [the Seebohm Committee], in 1965, to look at the local authority and allied personal social services. Their report, published in 1968, showed that little progress had by then been made in the move to community mental health services.

> Despite the national commitment to "community care" and official plans to run down the number of mental hospital beds, [local authority expenditure] still represents a small fraction of

> total health service expenditure for the mentally disordered. Although some local authorities have been remarkably successful in developing mental health services, there is a serious lack of staff, premises, money or public concern in other areas. The widespread belief that we have "community care" of the mentally disordered is, for many parts of the country, still a sad illusion and, judging by the published plans, will remain so for many years ahead [para.339] (Jones 1993).

At the same time, public attention had been drawn to another series of scandals concerning the treatment of patients in long stay hospitals. In particular, the revelation of the nature and extent of staff cruelty to patients at the Ely [mental handicap] Hospital in Cardiff in 1967, had ensured that services for the mentally ill were again high on the political agenda and that the usual round of inquiries and documentation followed (Dalley 1988) (Ham 1993). The processes by which certain issues become scandals are not, of course, necessarily linear and causal ones; they take place in particular moral and cultural contexts and often serve a variety of interests. As so often in this tale, it can be hard to distinguish chicken from egg when looking to unlock the reasons behind the course events have taken.

Against this backdrop, voluntary organisations such as MIND and Mencap were now becoming more prominent players in the debates. They campaigned vigorously for a raising of standards in these hospitals and a major rethink on current provision. The government responded with the establishment, in 1969, of the Hospital Advisory Service to visit and report on conditions around the country and of a major policy review, resulting in two White Papers, one in 1971 concerning services for the mentally handicapped and one in 1975 concerning services for the mentally ill.

3.4.1 1971: Keith Joseph's vision.

In 1970 Keith Joseph, then Secretary of State for the Social Services [which included the Health service] saw the answer to these scandals to be the reaffirmation of the policy outlined by Enoch Powell nearly ten years earlier. In a memorandum published in 1971, entitled "Hospital Services for the Mentally Ill" he predicted even lower numbers of in-patient beds than those foretold by Powell. Whereas Lord Ashley, in 1845, had seen the answer to similar scandals in the private madhouses to be the building of more institutions but ones that were better regulated and inspected, Keith Joseph, and the Labour ministers that followed him, looked rather to the destruction of that system and the return of the mentally ill to various community settings. Speaking

in the House of Commons in that same year, he gave clear support to the medical model of mental illness and to the further integration of psychiatry within the realms of general medicine.

> Psychiatry is to join the rest of medicine....the treatment of psychosis, neurosis and schizophrenia have been entirely changed by the drug revolution. People go into hospital with mental disorders and they are cured, and that is why we want to bring that branch of medicine into the scope of the 230 district general hospitals that are planned for England and Wales (Jones 1993).

Thus the official tale continued to be "close the old and outdated mental hospitals, treat people with mental illnesses at psychiatric units in general hospitals and then.....": but that part of the tale had yet to be made clear.

3.4.2 Better Services for the Mentally Ill [1975]

The 1975 White Paper concerned with services for the mentally ill was presented to parliament by Barbara Castle, as Secretary of State for Social Services in the Labour government. It was a cautious document, recognising the limitations on further development of these services at that time and tending to be pessimistic also about future prospects. Nevertheless it endeavoured to set out a strategic framework for development in mental health services, setting four broad policy objectives and has been described by a recent commentator as "a key reference point for the development of a national policy on mental health" (Hunter 1992).

The foreword to the document, written by Barbara Castle, opens with the acknowledgement that mental illness is a major health problem, but also gives credit to its social and environmental aspects. It confesses that there has been only slow progress towards the type of community care provision advocated in the 1959 Act and foretold by Enoch Powell saying, "what we have to do is get to grips with shifting the emphasis to community care. The problems are many." [p.ii] (Department of Health 1975). These problems are now seen to be not only the lack of community facilities and the staff to work in them, but also the lack of support for such developments within the community itself.

> We have to recognise, moreover, that the pace at which community based care can be introduced depends not only on resources but on the pace of response of the community itself....There is much scope for greater public understanding of the nature of mental illness. [p.iii]

Chapter Two of the White Paper offers an account of the development of services for the mentally ill which stresses their different needs now from in the Victorian era. Then they needed care and control: now, thanks to the introduction of the psychotropic drugs and of various forms of extra-hospital support, their needs are for short-term, hospital based treatment and rehabilitation, with after care provided in the community. It describes this as the underlying movement to community care. "Psychiatry was coming in out of the cold." [p.12] Mental health services could now expect to have a close relationship with both general health services and with local authority social services.

Nevertheless, the document recognises that progress has been very slow over the past decade and that "the failure....to develop anything approaching adequate social services is perhaps the greatest disappointment of the last 15 years." [p.14] A major shift of resources from Health Authorities to Social Services Departments would be needed to remedy this. In addition, the difficult financial climate will mean that progress over the next ten years is likely to be equally slow and difficult.

Despite this, the document continues:

> we believe that the philosophy of integration rather than isolation, which has been the underlying theme of development, still holds good, and that, for the future, the main aims must contrive to be the development of much more locally based services and a shift in the balance between hospital and social services care. [p.17]

The main obstacles and problems are discussed in more detail in the remainder of the document. Many of them remain pertinent twenty-four years later:

- gaining public support for the policy;

  "A humane service for the mentally ill requires the active concern of ordinary people as well as their tolerance." [p.18] The corollary to this is that there should be no "attempt to implement policies that depend on community tolerance faster than the community can adjust to them."

- the uneven and patchy development of community care; services across the country

- public fears about precipitate hospital closures.

  "We welcome this opportunity to stress that our aim is not the closure or rundown of the mental illness hospitals as such; but rather to replace

them with a local and better range of facilities." [p.84] The document pledges that the hospitals will not be closed until such facilities are in place and shown to be working well.

In 1976 the DHSS issued a consultative document entitled, "Priorities for Health and Personal Social Services in England." (Department of Health and Social Security 1976). It reaffirmed the development of community mental health services as a high priority and restated the concerns expressed in the White Paper. In the same year, new Joint Finance Arrangements were established in order to address the problem of shifting resources from health into social services to aid such development.

3.5 Moving into the 1980s; Has anyone seen community care?

The previous sections of this chapter have covered a period of many years remarkable for their pattern of much discussion of major changes in the provision of mental health services but little actual change. These services had been clearly recognised as a problem area, yet the solution to the problem, a move to community based care, appeared to be consistently easy to state but hard to achieve. By the end of the 1970s it remained the case that there was little clarity about either the idea or the practice of such community care and little enthusiasm to set about implementing it. At an organisational level, the lack of any effective collaboration between Health Authorities and Social Services Departments, despite attempts to improve the mechanics of joint working, coupled with their history of rivalry for resources, the unclear demarcation line between health and social care and the competing pressures from other areas of local authority responsibility, set the scene for continuing problems and dilemmas.

At a broader level, the country's economic difficulties in the 1970s had crucial repercussions upon the role of the state in welfare provision generally. 1979 is often seen to have marked a watershed in British post-war social policy, ending the cross-party consensus based around the ideas of Beveridge and Keynes, which gave the state a central role in welfare provision (Hudson 1990). Whilst this consensus view held sway, the community care proposed by the Percy Commission in 1959 could be assumed to take the form of publicly funded care in locations other than the old mental hospitals. After 1979 however, the emphasis shifted. The Conservative government led by Mrs. Thatcher, with little ability and less desire to increase state expenditure on welfare, looked rather for a new variant, a model that included more

privatised care and care by the community.

Increasingly government and other official pronouncements began to focus on elements of informal, family and private sector care in the composition of community care; for example the 1979 Report of the Royal Commission on the NHS stated:

> community care is provided primarily by family and neighbours, with the support of the health and personal social services.

This theme was developed in the 1981 White Paper, "Growing Older", which stated that:

> the primary sources of support and care for elderly people are informal and voluntary....It is the role of public authorities to sustain, and where necessary develop, but never to displace, such support and care. Care in the community must increasingly mean care by the community (Department of Health and Social Security 1981*b*).

If the original intention for the ending of the community care tale had been that the responsibility for providing that care should rest primarily with local authorities, it now looked as if, given their failure by and large to do so, that role would be officially placed upon families and friends. This idea was fiercely criticised by feminist social policy analysts who pointed out the assumptions about women's caring roles inherent in it and the burdens it would place upon them (Dalley 1988) (Finch 1989) (Qureshi & Walker 1988) (Ungerson 1987).

3.5.1 The influence of normalisation

The continuing confusion around the role and nature of community care was highlighted from another angle with the introduction of Wolfensberger's ideas on "normalisation". These are complex, both in origin and development, but are generally understood to be concerned with ensuring that services support their users to achieve community integration and social participation and challenge negative portrayals and labelling (Brown & Smith 1992). His work, although originally undertaken with people with learning disabilities, soon came to be applied to a number of client groups, including people with mental health problems. His ideas were incorporated into the 1980 Kings Fund document "An Ordinary Life" (Department of Health and Social Security 1981*b*), and laid down a challenge to the current cultural stereotypes of ageing and disability. By opening up a space for service users, carers, front line

staff, managers and policy makers to re-examine and re-conceptualise their beliefs and practices, the ideas of normalisation also threw the spotlight onto discussion of the basic principles and values that should underpin community care (Hunter 1992).

3.5.2 1981: "Care in the Community."

The discussion was taken up in 1981 in the consultative document issued by the Department of Health and Social Security called "Care in the Community" (Department of Health and Social Security 1981*a*). It focused on a study of community care for older people and those with mental health problems who needed some form of long term care and had been identified as being at risk of receiving a second rate service. The fear was that, whilst people with acute and treatable conditions were being attended to in the psychiatric units of general hospitals, older patients and those with chronic conditions were being left behind in a planning void awaiting the development of community care services.

The document's terms of reference were:

> to clarify policies for the development of community care for the health and personal social services, in terms of the resources now expected to be available, including self help, the contribution of the voluntary sector and the contribution of the private sector.

Its stated aim was to stimulate local discussion and it confessed to "some uncertainty about the general policy objectives underlying the concept of community care" [p.1] and queried whether "present service and client group policies which imply a shift away from long term institutional care were realistic."

However, despite these doubts and uncertainties, the document went on to state that:

> we should stress here that it was not the purpose of the study to question the philosophy of community based care. There is little doubt about the benefits to be gained from providing for people's needs in a flexible way, which maintains their links with ordinary life, family and friends whenever possible and offers greater choice.

Chapter Two of the document attempted to unravel some of the confusion around the term that stems not only from its use as both a description of the services and resources involved and as a statement of objectives but also from

the ambiguities within each of these usages; for example, within the health service a move from a long stay institution into a residential home might be seen as a move into community care, but living in such a home would not be included within a social service definition. However, the document concluded that it would not be helpful to try to produce a definitive account of what community care is or means, thus allowing the confusions to continue and multiply and failing to give a clear lead to service planners.

The findings from the document were addressed by a 1983 circular "Care in the Community and Joint Finance" (Department of Health and Social Security 1983), which reaffirmed a commitment to the incremental approach to the development of community care services, rather than looking for any radical initiatives beyond making some money available to fund a programme of care in the community pilot projects (Means & Smith 1994).

3.5.3 1983: The Mental Health Act

This was the major piece of mental health legislation of this period and, as such, offered an opportunity to reflect on the nature of mental illness as now understood and to address the many concerns outlined above about the best way to respond to it. However, this opportunity was not taken up. Instead the Act concentrated upon legal safeguards around compulsory detention, the rights of individual patients to refuse treatment and the introduction of the Approved Social Worker system and of guardianship orders. By this emphasis upon individual patients in hospital it too contributed to the failure to develop services to meet the needs of those, the majority, hoping to be supported in community settings. There is very little in the Act that goes beyond the individual patient to highlight instead the character and limitations of the services they were experiencing. Even the watchdog it established to protect people who were detained under its sections [the Mental Health Act Commission], consistently failed to do so, as later scandals were to reveal.

3.5.4 A flood of problems and criticism

Despite the continuing official commitment to a move to community based mental health services, by 1983 not one hospital had yet closed and many problems and dilemmas remained unresolved. A planning blight lay over the old hospitals for there was no incentive to invest in their upkeep, let alone in any improvements, if they were shortly to be closed. Yet how could they be closed until there was other provision to replace them? Whilst a vague and confused definition of community care might have the advantage of securing a broad range of support for it in principle, it also had the disadvantage of

making it hard to implement in practice or to convince people that there was a genuine commitment to it. Therefore, local authorities, faced with much clearer and more strenuous demands for money from other quarters, with only permissive rather than mandatory powers to develop community care provision and aware of a weight of opposition to the policy building up from stakeholders, such as COHSE and psychiatrists, were unlikely to be establishing the community provision which would make it possible to close the hospitals.

One of the pressures which finally drove the government to bite the bullet, rather than allowing this situation to drag on, came from changes in the social security system introduced in the early 1980s, which gave rise to a very rapid growth in the number of private residential and nursing home beds from 46,900 in 1983 to 161,200 in 1991. This took place at huge cost to the public purse, since people were entitled to a subsidy for the cost of these places based only on financial circumstances not on an assessment of need. The Conservative government could not allow this to continue, not only because its aim was to limit, not expand, state involvement in welfare provision, but also because it provided a perverse incentive to the development of residential care when the government wished rather to encourage the development of domiciliary services.

It was a House of Commons Social Services Committee which took up the challenge of addressing the structural failings of the mental health services, in a report issued in 1985 (Social Services Committee 1985). Athough twenty four years had passed since Enoch Powell's speech, the Committee had to acknowledge that:

> we are now at a crucial stage in the development of community care policies....The stage has now been reached where the rhetoric of community care has to be matched by action. [para.223]

The report lamented the continuing failure to develop a coherent community care policy for adults suffering from mental illnesses and handicaps. It re-iterated the fear that the rate of hospital rundown was outstripping the development of community services and that such policy as there was concerned itself only with enabling the discharge of people currently in hospital rather than with ways to develop services for many people in the community. It called for an agreed philosophy and consensus on what constituted good community care, giving as its own opinion that it must be based upon ordinary housing.

> Appropriate care should be provided for individuals in such a way as to enable them to lead as normal an existence as possible,

> given their particular disabilities, and to minimise disruption of life within their community. [para. 11]

In general terms, it visualised a community care policy that privileged home over institutional settings; normalisation and integration over restriction and segregation; small units over large; and local provision over distant [para.10].

Finally it argued for greater involvement of service users and carers in the design and planning of these services, stronger joint planning mechanisms, an increase in resources and a central bridging fund to cover the time of double running as community provision was developed prior to hospital closure.

The government issued a brief response to the report in November 1985 (Department of Health and Social Security 1985). It was far from enthusiastic about the report's suggestions and refused to provide more resources or a bridging fund. It re-iterated government support for community care as both a philosophy and a practical proposition, but skirted away from any attempt to provide a clear definition of it, preferring instead to keep to the most general of terms.

> Community care is a matter of marshalling resources, sharing responsibilities and combining skills to achieve good quality modern services to meet the actual needs of real people, in ways those people find acceptable and in places which encourage, rather than prevent, normal living. [p.1]

It thus emphasised local responses rather than national guidelines: a welcome chance for the flexibility to respond to local circumstances and needs, or a convenient way to shift responsibility and blame from central government?

However, the relentless pressure upon the policy, or the lack of it, continued to build. The next assault came from the Audit Commission in their 1986 report, "Making a Reality of Community Care" (Audit Commission 1986). It highlighted the slow progress being made towards community care, especially for people with mental health problems, the patchy and uneven nature of such provision as there was and its often continuing institutional nature.

The report identified five underlying problems:

- a mismatch of resources;
- the lack of a bridging fund;
- the perverse effects of the social security policy;
- organisational fragmentation and confusion;
- inadequate staffing and training.

It also specified five characteristics of good community care:

- strong local champions of change;
- a focus on action not bureaucracy;
- locally integrated services;
- a focus on the local neighbourhood;
- a multidisciplinary team approach.

It concluded by stressing the need for strategic thinking, national clarity as to the responsibilities of the various agencies involved and an urgent, high level review, saying:

> what is not tenable is to do nothing about the present financial, organisational and staffing arrangements [para.177].

3.6 1987-1990: More calls to action and the new community care.

The problems and concerns highlighted in connection with community care and mental health service provision in the early 1980s were, as previous sections of this chapter have shown, not new; rather they had been present from the very start in the 1960s and a succession of people and agencies had, as shown above, been called upon to resolve them. Although the problems had not changed, the social, political and economic context in which they were being experienced had. The Conservative government of the 1980s was committed to an ideological transformation across government policies that, combined with the financial restraints of the times, meant a re-orientation of the state's attitude to welfare provision; a "rolling back" of the state's involvement. Although, in practice, this shift had been slow to take place so far, that was about to change. As Julian Le Grand has pointed out:

> One of the more curious features of the first two Conservative administrations under Mrs Thatcher, was how little impact they had on the welfare state. With the major exception of council house sales, the basic structure of the welfare state in 1987 was much the same as in 1979....The peace was not to last. A major offensive against the basic structures of welfare provision was launched in 1988-9; years that, in retrospect, will be seen as critical in the history of British social policy. For it was then that the

> Conservative government began to apply a programme of radical change to the welfare state (Le Grand 1990).

3.6.1 1987-8: Firth, Wager and Griffiths

Three major reports were issued in these years, all springing from governmental concern about the community care policy, although this concern centred on financial aspects.

Joan Firth, as Chair of the Department of Health and Social Security Select Committee, was asked:

> to review the arrangements for financial support for residents in Local Authority, private and voluntary residential care homes....and to make recommendations for a coherent system of financial support which aims to combine flexibility and responsiveness to individual needs and circumstances with the optimum use of public resources.

Gillian Wagner chaired a committee set up by the National Institute for Social Work and was also asked to review the role and costs of residential care.

Roy Griffiths was asked, by Norman Fowler, then Secretary of State:

> to review the way in which public funds are used to support community care policy and to advise me on the options for action that would improve the use of these funds as a contribution to more effective community care.

The government thus set the terms and starting point of the debate, reflecting its concerns. The answers that it took up came mostly from one man, a businessman, who, as Managing Director of Sainsburys, might seem to personify Mrs Thatcher's belief that the public sector had much to learn from successful private enterprise and who had indeed been called in before [1983] to look at health service management. As Walker has argued, the government thus continued to ignore the confusion and ambiguity around the aims and goals of the community care policy. Clarifying these might have been a more helpful start, from the point of view of people with mental health problems, before setting out, as these reports did, to decide on the most suitable managerial arrangements for it (Walker 1989).

The Griffiths Report, "Community Care:agenda for action", was the one which had the most impact and received the most widespread reaction. It was published in March 1988, in the form of a short document concerned

with management issues. It acknowledged that there had been problems in trying to implement the policy thus far:

> At the centre, community care has been talked of for thirty years, and in few areas can the gap between political rhetoric and policy on the one hand, or between policy and reality in the field have been so great [para.9] (Griffiths 1988).

It went on to describe community care as "a poor relation; everybody's distant relative and nobody's baby." It looked for solutions to these problems in better management techniques, clearer responsibilities and firmer lines of accountability. Its main recommendations were:

- to appoint a Minister for Community Care, with a strategic role;
- to make local Social Service Departments the lead agency for all the community care client groups;

  The Audit Commission [1986] had suggested that Health Authorities take the lead role for people with mental health problems. This report, to many people's surprise, left SSDs as the lead agency but with a new role as an enabling authority, not as the sole provider of services. Their job would be to identify local individual needs and then design and co-ordinate a package of care to meet those needs, purchased from a mixed economy of private, voluntary, statutory and informal care
- to compel Local Authorities and Health Authorities to produce joint, annual community care plans for inspection and approval by the Minister;
- to introduce into the social security funding for residential care separate assessments of finance and of need, to be administered by the social service department.

Means and Smith, in their discussion on this report, identify four main themes running through its recommendations:

- to provide links between the objectives of community care policy and its funding by central government;
- to clarify the responsibilities and boundaries, at local level, for health authorities, social service departments, housing organisations and voluntary and private organisations;
- to stimulate choice through a mixed economy approach to care provision;

- to cap the current, open ended social security payments for residential care.

and, overarching all of these, the stated desire to change only the management system, not to completely re-organise the structure (Means & Smith 1994).

The report was written in the language of managerialism and so placed within the wider debate on how best to manage large organisations, but without any reference to debates on the role of the state in welfare provision, the nature of caring, disability or ageing or the role of service users in care provision. It used the language of the market place as though it were value free and could be easily translated from one arena to another e.g. from private to public sector, from buying and selling to caring, from competition to public service. As Trevillian has observed, "in effect Griffiths de-politicises community care and offers us a sanitised vision of community as a well regulated supermarket" (Trevillian 1988).

3.6.2 What image of community care?

It was this language and vision that continued to set the dominant tone for official discussion of the future of community care. However an alternative public vision existed and was being developed. As some of the old mental hospitals did finally start to close down completely [35 closed between 1980 and 1990, and the average in-patient population in the remaining ones fell to c.300] media attention began to turn to the lack of alternative provision and the plight of some of the hospitals' former residents. The dominant image picked out there was not the bright lights and smiling faces of the smooth running supermarket, but groups of people with mental disorders huddled, shivering, amongst the homeless under grey, inner city bridges.

> There are hundreds, if not thousands, of mentally ill people living unsupported in the community, many of them former hospital patients. Large numbers are sleeping rough in archways and under railway bridges, some within hailing distance of the Palace of Westminster (Social Services Committee 1985).

User groups, such as MIND and the National Schizophrenia Fellowship [NSF], were becoming more highly organised, vocal and visible. NSF published their own 20 point plan in 1989, which called for the retention of some long stay hospital provision to offer asylum from the stresses of modern living and criticised the current arrangements for hospital resettlement programmes on the grounds that they had been poorly thought through and were being carried out too hastily.

The dangers with this new public image of madness and community care were that it presented only one aspect of service users' experience and that it could, as in the past, be used as a convenient humanitarian gloss to cover the public's own unease about finding itself once more in close proximity with people with severe mental illnesses and desiring a return to a segregative system of care.

3.6.3 1989: "Caring for People, community care in the next decade and beyond"

There was a long delay [18 months] between the publishing of the Griffiths Report and the issuing of the White Paper "Caring for People", which took up most, but not all, of the Report's recommendations. A variety of explanations have been offered for this delay including dismay at many of the Griffith Report's recommendations, especially earmarking funds for community care, which would identify the level of government commitment to them and extending the powers of local authorities, and a desire to seek an alternative to them, plus greater concern with pressing problems in other areas of social policy (Means & Smith 1994) (Lewis & Glennerster 1996) (Hudson 1990).

When finally published, in November 1989, the proposals were that social service departments strengthen their lead role in the provision of community care services, although as enabling authorities rather than remaining as the dominant providers of care. Their main operational duties, as per Griffiths, were to be assessing individuals' needs, designing packages of care to meet those needs and enabling the development of services from various sectors to deliver those care packages, through the co-ordination of a care manager. At a strategic level, social services were to produce joint community care plans with the other relevant agencies, such as health and housing. However, there was to be no minister for community care nor any earmarked funds, beyond a new specific grant "to promote the development of social care for seriously mentally ill people." [para. 1.12] Although keen to clarify lines of accountability and responsibility for local agencies, the Government seemed much less keen to see the same mechanisms put in place for its own contribution.

The Foreword to the document states:

> Helping people to lead, as far as is possible, full and independent lives is at the heart of the government's approach to community care....We believe that the proposals in the White Paper provide a coherent framework to meet present and future challenges....Our aim is to promote choice as well as independence (Department of Health 1989).

Choice, independence, control and homely settings are key words in the document's discission of community care. Chapter One sets out the government's approach:

> The Government believes that for most people community care offers the best form of care available–certainly with better quality and choice than they might have expected in the past. The changes outlined in this White Paper are intended to:
>
> - enable people to live as normal a life as possible in their own homes or in a homely environment in the local community;
> - provide the right amount of care and support to help people achieve maximum possible independence and, by acquiring or reacquiring basic living skills, help them to achieve their full potential;
> - give people a greater individual say in how they live their lives and the services they need to help them to do so.
>
> Promoting choice and independence underlies all the Government's proposals [para. 1.8.].

The document goes on to set out four key components of community care:

- services that respond flexibly and sensitively to the needs of individuals and their carers;
- services that allow a range of options for consumers;
- services that intervene no more than is necessary to foster independence;
- services that concentrate on those with the greatest needs. [para. 1.10.]

It identifies six key objectives for service delivery:

- to promote the development of domiciliary, day and respite services to enable people to live in their own homes wherever feasible and sensible;
- to ensure that service providers make practical support for carers a high priority;
- to make proper assessment of need and good case management the cornerstone of high quality care;

- to promote the development of a flourishing independent sector alongside good quality public services;
- to clarify the responsibilities of agencies and so make it easier to hold them to account for their performance;
- to secure better value for taxpayers' money by introducing a new funding structure for social care. [para. 1.11.]

Despite its title "Caring for People", and the statements about the values underlying and approach to community care that it envisages, the suspicion has persisted, based on events both prior and subsequent to its publishing, that the government's real aims and concerns with regard to the development of community care in fact lay quite elsewhere. Given the ideological thrust of the Conservative Government of the day and the broader international context, it seems likely that its main concern was with capping the runaway spending in the social security budget in ways that would provoke as little public outcry as possible and extend the powers of local authorities as little as possible. The talk of fostering choice and independence and developing a culture of needs-led services, whilst attractive to service users, carers and social services departments, was always going to be in difficulties once it ran into the quite contrary desire to curtail public expenditure.

Since this "new" community care was intended to cover a number of different client groups, the document included a chapter specifically about services for people with a mental illness [chapter seven]. In it the Government "recognises the justified concern about the availability of community services for mentally ill people" and describes three key initiatives to tackle it:

- the introduction of the Care Programme Approach [CPA];
- asking Regional Health Authorities to identify sites for developing private sector involvement in building new facilities;
- the introduction of the Mental Illness Specific Grant [MISG]. [paras. 7.6 -7.17.]

It traces the move to community care for people with mental illnesses back to research demonstrating that their treatment is as good if not better when administered in community settings and to the introduction of the major tranquillisers in the 1950s, which have "transformed the prognosis of the most serious mental illnesses." [para. 7.4.] It recognises the concerns about inequitable provision across the country and the premature closure of the long stay hospitals. Nevertheless it claims that:

> Where it is effectively implemented, the new style of service offers a much higher quality of life for people with a mental illness and a service more appreciated by their families than is possible in the traditional large and often remote mental hospital. The Government reaffirms its support of the policy as a civilised and humanitarian one. [para. 7.4.]

3.6.4 1990: The NHS and Community Care Act

On June 29th. 1990 the NHS and Community Care Act was passed, but, only a few weeks later, on 18th July, was followed by a ministerial statement that it would not, as expected, be implemented in full as from 1st April 1991 but would rather be implemented in three stages between April 1991 and April 1993. The official explanation was that this would give local authorities more time to prepare adequately for the changes but the suspicion was that, once again, instead of offering a clear and definite commitment to the implementation of community care in practice as well as in policy statements, the Government was still far from happy with the proposed changes and more concerned with its own financial and political considerations and with reforms in other areas, such as the introduction of the NHS reforms, the problems with the levying of the community charge and the introduction of local management of schools.

Despite the flurry of activity and documents, community care seemed to have gone missing yet again.

3.7 Conclusion

This chapter has continued the mysterious tale of the mental health services from 1930 until 1990, focusing upon the many attempts to formulate for them an alternative to segregative, hospital based care. However, these attempts to develop community based care for people with severe mental illness have been dogged by all the difficulties that surrounded the old pattern of institutionally based care and several new ones besides.

The 1930 Mental Treatment Act was chosen as the starting point of the chapter because it clearly marked out mental distress as an illness, similar to physical illnesses, thus ensuring its place within the wider health services remit and debates. It was also the first to give to local authorities the power, if they so wished, to develop other sites for its treatment and care. Although very few took up this opportunity in practice, nevertheless the idea of providing treatment and care in other locations continued to grow and be

nurtured by both politicians and psychiatrists, now armed with new, psychotropic drugs. Consequently, when the Percy Report and then the Mental Health Act were published in 1959, the official view had become that mental illnesses were better treated in community settings. This Act foresaw the gradual scaling down of the old mental hospital provision, but not what was to replace it besides acute treatment at District General Hospitals. As mental illnesses became conceptualised as more like physical illnesses, some part of the space allotted to physical illnesses was turned over to them but the differences between the two were not equally acknowledged and provided for. In addition the conceptualisation was more that of an acute than chronic illness and so allowed many of the medical aspects of the response to mental illness to be transferred from the asylum to the DGH without a full commitment to reproviding the other aspects of care.

In the 1960s, following Enoch Powell's famous speech, the idea of providing for mental illnesses in the community continued to be developed, not only in Britain but throughout other countries also. In Britain, although it was generally understood to be publicly funded provision outside the old long stay hospitals, it was never clearly defined, discussed or funded. Despite this lack of clarity, by the late 1960s the remit of community care had widened to include services for older people, people with physical and sensory impairments and people with learning difficulties. The previous chapter has shown the difficulties inherent in providing support and treatment for mental illnesses alone, given the conceptual problems around defining them and society's response to them. Placing decisions on the provision of such services together with those for other client groups did nothing to help to clarify these problems.

By the time that some of the organisational barriers to the development of community care services had been overcome, through such things as the new joint finance arrangements in the 1970s, the country's financial circumstances had changed and the dominant ideas and consensus on state welfare provision were about to change in their wake. The 1975 White Paper, "Better Services for the Mentally Ill" acknowledged the difficulties, both financial and ideological, implicit in a move to community care, but clung nevertheless to the aim of "integration not isolation" and of locally based services. It also highlighted the lack of public support for, and indeed opposition to and suspicion of, the policy; in particular fears that the old hospitals would be closed prematurely, with little or nothing to replace them.

By the 1980s it was obvious that there had been very little actual progress towards the provision of community care and inequitable distribution across the country of such services as there were. The lack of any clear commitment to the implementation of the policy from any government had left most local

authorities too apprehensive and uncertain to risk committing their scarce resources to it. In addition, its successful implementation seemed to depend upon close joint working between health and social services, which was, in itself, extremely difficult to achieve. As successive Conservative governments developed their ideas on the restructuring of the welfare state, such a hazy vision of community care as had been developed began to change also in ways that gave much more emphasis to its elements of informal, voluntary and private sector care, describing these as "the primary sources of support and care." The policy documents of this time openly acknowledge the continuing obstacles, confusion and uncertainty about community care as both a term and a policy. If politicians, policy makers and psychiatrists felt confused, that was as nothing compared to the difficulties being experienced by people with severe mental illnesses as the old psychiatric hospital provision declined with very little to reprovide its medical, social, economic and cultural "spaces". Such attention as there was to these problems concentrated upon people who were currently in the old hospitals and what, largely medical and physical, alternative spaces should be provided for them, ignoring the troubles of the many people attempting to maintain their lives in the community.

It is significant that the issue that did manage to concentrate the minds of politicians and policy makers once more upon community care in these years was that of the spiralling costs of providing residential care, which arose unexpectedly from changes in the social security system, and the failure to actually close any of the old, and expensive, institutions. Having framed the problem in financial and managerial terms, they sought an answer to it from Roy Griffiths, a businessman. His solutions lay in establishing clearer lines of responsibility and accountability, a new enabling role for social service departments, a separate assessment of finance and of need for residential care and the introduction of markets and consultation with "consumers" into welfare services. Even his solutions were not entirely acceptable to the government but, nevertheless, formed the basis of the "new community care" described in the 1989 White Paper "Caring for People", and enacted into legislation the following year, in the NHS and Community Care Act.

Sadly, as details of this new vision for community care began to unfold, the government immediately backtracked, slowing down the planned timetable for its implementation and grappling with a more engrossing problem in the resignation of the Prime Minister, Mrs Thatcher and the ensuing leadership contest. At the same time, a public and media backlash against community care, particularly for people with mental health problems, was growing rapidly, although it was hard to be clear whether it was driven by concern for the welfare of those with mental illnesses, or by a desire to have them removed from a proximity which the rest of society found too close for

comfort.

The policy documents from this period display the various changes in meaning that the term "community care" underwent; from referring simply to care given by professionals outside large institutions, to professional care given outside all hospital settings, to a concern with supporting care by the community and promoting choice, independence, integration and "ordinary living", in local and homely settings. These changes made it difficult enough to grasp the concept on paper and many commentators felt that it never did become a fully thought out, internally coherent and externally explicit policy (Knapp & et al 1992).

> There must be serious doubts about whether a coherent policy exists at all. There is every likelihood that a policy vacuum will emerge, which could put the future shape and direction of community care policy back into the melting pot (Hunter 1992).

Yet it was also always acknowledged that there was a very large gap between even such rhetoric and any reality on the ground for this policy area. In any case, health and other welfare services are never merely a reflection of government policies, however knowledgeable and well thought through they might be. There are many layers of interpretation and local practice even before each particular professional enters upon a caring relationship with any individual. Practitioners, as well as politicians, have their own agendas to pursue. Nevertheless, for those people who are living with severe mental illness, their situation would be more easily understood if there were a clear policy both developed and openly communicated by central government.

> Should we believe what politicians tell us in their white papers? These are political documents designed to win support and hide unpopular purposes, and can be used to obfuscate rather than clarify policy objectives. Trying to decide what policy a government is actually aiming to pursue is in itself a controversial matter (Lewis & Glennerster 1996).

Political and academic commentators, local policy makers and managers have all remarked upon the many uncertainties, tensions and dilemmas still present within community care.

> The problem with all this intense speculation over what precisely the government's policy is concerning community care, is that it diverts attention and makes developments difficult to plan, finance and implement, because no-one dare do so with any confidence. Managing uncertainty is one thing. Managing political vacillation on a grand scale is quite another (Titterton 1994).

Managing a life with severe mental illness in these circumstances might prove to be more challenging still.

4. NEW SPACES, NEW RELATIONSHIPS? USERS IN THE HEALTH AND SOCIAL SERVICES

4.1 Introduction

The previous two chapters of this thesis have, by examining the changing physical spaces made available for mental illness since 1800, demonstrated the continuing confusion within mental health policy and the ways in which that is linked to our society's continuing uncertainty about how to respond to people with mental health problems. This chapter will focus on the moral and social "spaces" provided for mental illness, by examining policy documents from 1990–96, the ways in which they have been implemented and their implications for the relationships that mental health service users are currently deemed able to have, both with mental health professionals and with wider society.

The last twenty years have seen an increasing focus upon the user across the whole range of public services. From transport to town planning, from education to policing, the call has been to make services more responsive to the needs and wishes of their recipients. For staff in these services, this has meant the adoption of at least the rhetoric of "user-centred services". For some users at least, it has meant that they have been offered opportunities to voice their opinions about the planning and delivery of services. In many ways, of course, users have always been central to the health and welfare services, since without them the rest of the enterprise is redundant. However, it is only recently that their role has come to be openly acknowledged and their input into decision making encouraged –in policy documents, at least; for with "user involvement" as with "community care", the gap between rhetoric and reality can be large indeed.

The passing of the NHS and Community Care Act and the subsequent guidance on its implementation, has, in theory at least, many repercussions

and implications for the users of mental health services. The setting out of a framework for the provision of community care services based upon a multi-disciplinary needs assessment followed by the drawing up of an appropriate care package purchased from a range of statutory, voluntary and independent providers, under the aegis of a Care Manager, has led to huge organisational and philosophical changes for the statutory agencies. However, many people in receipt of these services remain largely unaware of these (Barnes 1997).

The aspect of the Act and guidance which may have more resonance and import for them, is that which focuses on the role of service users, for the White Papers "Caring for People" and "Working for Patients" on which they were based spoke of "promoting choice and independence" and of giving people "greater individual say in how they live their lives and the services they need to help them to do so" (Department of Health 1989).

This chapter will examine the role allotted to service users prior to this Act, and the new spaces and relationships that may be made available to them under the new dispensation. Previous chapters have discussed the changing locations of mental health services over the past two hundred years and shown how these were linked, although not in any simple linear fashion, to changing ideas on the nature of mental distress and the ways in which society should respond to it. These ideas have always been confused and often contradictory; different strands of thought have persisted and developed over the years, with certain ideas gaining greater dominance at certain times. Because mental illness has always been a contested concept, the spaces –social, moral and economic, as well as physical– available for people with mental health needs have also always been uncertain and controversial. What may be different about them as we enter the new millennium, is the opportunity now being offered for service users themselves to enter the debate and to influence their "shape".

The NHS and Community Care Act lays emphasis upon the provision of services which are appropriate to and responsive to their users' needs. To help achieve this, it calls for greater user involvement in decisions both about their own, individual care and about wider service planning and development. However, following the pattern of past documents, the Act and guidance are far from clear in defining what the nature of such involvement might be. Research undertaken to examine it has revealed wide variations in practice and in the understandings of both "involvement" and "users" (Glendinning & Bewley 1992) (Ellis 1993) (Stevenson & Parsloe 1993).

4.2 Origins

As always, an understanding of the historical background is helpful in illuminating current problems and confusions.

4.2.1 Public participation: the 1960s and 70s

The 1969 Skeffington Report "People and Planning", and the 1968 and 1971 Town and Country Planning Acts placed a duty upon local government to carry out public consultation in planning for land use and for a public appeal system against such decisions. This development in land use planning has been described by Croft and Beresford as marking:

> the first large-scale, government intervention in "participation". It introduced the term, "public participation", into the political vernacular. It anticipated provisions for consultation in community care planning contained in the NHS and Community Care Act by 20 years, and, through it, many community organisations became involved in planning issues (Croft & Beresford 1992).

If this is the first "top-down" appearance of public participation in official policy, the "bottom-up" influences that contributed to its appearance at that time and in that form are to be found in a variety of sources.

The policy and practice of community development and community action had also gained ground during these years, largely based upon the studies of community life undertaken in the 1950s and 60s. As a result, the 1968 Seebohm Report, which gave rise to Local Authority Social Service Departments in England and Wales, envisaged the community as both a network of social relations, which provided care, and as something which itself needed to be cared for. Consequently the report advocated the employment of community workers as well as individual case workers, in order to support individual and group involvement in the planning and provision of services (Barnes 1997) (Smith 1988). Similar ideas and developments within the health service, as well as the series of highly publicised scandals in long stay hospitals and well developed critiques of them, led to legislation in 1973 establishing Community Health Councils to "represent the interests of the public in the health services in their district."

At the same time, a series of radical critiques of traditional power had found concrete expression in the formation of a variety of groups and organisations which have come to be known as new social movements (Rogers & Pilgrim 1996) (Oliver 1990). They included groups for Black people, women, and gay and lesbian people. Unlike the older social movements based around

class and labour, these groups were based upon common identity and issues of social relationships. As Barnes has pointed out:

> new social movements have demonstrated the spurious solidarity underpinning class politics and have enabled those excluded from such organisations to become empowered within social groups which reflect the differences which exist within contemporary society. They bring new voices into political dialogue, challenging dominant values and causing dominant groups to re-assess their own perspectives (Barnes 1997).

The struggles of these groups for the inclusion of marginalised and oppressed people fed into the subsequent growth of service user groups which also were based upon shared identity and experience, even if they also contained within themselves a host of differing aims and ideologies. Wolfensberger's ideas on normalization were starting to become influential amongst staff working with people with learning difficulties whilst, within the mental health services, the critiques of psychiatry offered by Szasz, Laing and Cooper fuelled the rise of new campaigning organisations of mental health workers and patients, such as "People not Psychiatry" and the "British Network for Alternatives to Psychiatry." Challenged and changing conceptions of mental illness made possible the, at least partial, acceptance of new conceptions of people with mental health needs. Although the UK lagged behind other countries, especially the United States and the Netherlands, in the development of a user movement in mental health, the 1970s saw the formation of the first patient only and patient-led groups, the Mental Patients Union and Prompt [Protection of the Rights Of Mental patients]. These were short lived and had little impact at the time, but were important because they undertook the initial groundwork that enabled later groups to achieve more (Rogers & Pilgrim 1991).

Changes within industry and the economy may also have contributed to the interest in public participation in public services. The economic boom of the 1960s gave birth in the 70s to criticism of centralised bureaucracies and to the rise of the language of consumerism in the commercial world, as technological advances made possible more flexible and decentralised production processes; a move known as Post-Fordism. These ideas were taken up within the public sector, which was now facing increasing dissatisfaction with the existing welfare state, framed in similar terms. It looked, therefore, to parallel changes in the ways in which it delivered its services –from mass production and consumption of centrally standardised services to flexible and locally produced services responsive to the particular needs of those using them (Means & Smith 1994) (Barnes & Wistow 1992).

These developments in new visions of production and distribution; in ideas of community work in health and social services departments and in the self organisation around identity of the new social movements were all part of a widespread challenge being issued at the time to traditional authority of all sorts, to the right of professionals alone to make decisions, to the bureaucratic paternalism of the health and welfare services. This period has been described as "the era of social protest and liberation movements" (Read & Wallcraft 1992). It witnessed government legislation across health, education, social services and housing, all concerned to increase user involvement in service planning and delivery. However, the origins of this concept come from diverse, and sometimes conflicting roots, and its development has been overshadowed by problems familiar from the discussion in previous chapters of the history of the lunatic asylum and of community care policy, in that rhetoric has rarely matched reality, that the terms employed have never been clearly defined and that the aims intended to be achieved were often confused and contradictory.

4.2.2 Consumers or citizens? The 1980s

By the end of the 1970s the pressure from campaigning groups for equal opportunities and anti-discriminatory practice had contributed to some changes in public and professional perspectives and attitudes across the health, education and social services. However, when these came to be put into practice during the 1980s it was within a very different social and political context from the one in which they had been conceived.

Under the influence of successive Conservative governments, the policy support for public participation transmogrified into a drive towards a consumerist ethos in public services driven by market economics, situated within an enterprise culture and displaying a much reduced role for the state coupled with the vision of increased choice for the consumer/service user (Means & Smith 1994).

This development can be traced through a series of documents across a range of social policy areas. The Barclay Report [1982] supported the development of neighbourhood social services and community social work. The Short Report [1984] argued that, in the fields of mental illness and mental handicap [sic] the aim must be to match the service to the consumer not, as presently, to fit the consumer into the available services, but pointed out that this was hard to achieve at the moment because "we had difficulty in hearing the authentic voice of the ultimate consumers of community care". The Audit Commission repeated this aim in their report "Making a Reality of Community Care" [1986]. In the same year the Disabled Persons Act sup-

ported the involvement of disabled people in planning their care. The Wagner Report [1988], examining residential care, proclaimed that, "residents are entitled to be involved in all decisions which affect their daily lives". In 1988 the Education Reform Act introduced the local management of schools and the Griffiths Report set out a framework for community care in health and social services. In 1989 the Children Act allowed children to participate in decision making about their care and the White Paper "Caring for People" stated its aim as "to give people a greater individual say in how they live their lives and the services they need to help them to do so."

Each of these documents called for active user involvement in local services; a call which was supported across the political spectrum. However, beneath this veneer of consensus over the value of user involvement, there lurked, once again, a hotch-potch of very different aims and ideologies, a hornet's nest of conceptual, policy and practice confusion around involving users that still bedevils its implementation.

The achievement of a surface consensus was possible because this was a period when the existing welfare state was under criticism from all parts of the political spectrum. Those on the left viewed the current welfare services as being too bureaucratic, paternalistic, oppressive and de-humanising, and sought to address those problems through greater user involvement. Those in the political centre saw the current services as ineffective and unresponsive to individual situations, and sought to address these problems through decentralising services and increasing voluntarism and user involvement. Those on the right of the spectrum saw the current services as a "nanny" state which caused problems rather than solving them, because they created dependency and sapped initiative, enterprise and morale. They sought to address these problems through the introduction of a market based model of welfare services offering greater individual choice and efficiency, through competition between providers; a model which also called for consumer involvement (Smith 1988) (Means & Smith 1994).

It was this latter model, the new right's consumerist model of user involvement, that underpinned the official policy documents of the period under the Conservative governments. By the late 1980s this model had developed into a rhetoric of the users of welfare services as active consumers involved in making decisions about their individual care. As befitted its market-driven approach, the involvement on offer for these active consumers had a customer service ethos, being management-led and making use of market tools such as customer surveys and market research, complaints procedures and standard setting. It aimed at increasing individual choice of service and improved quality through competition between providers.

In reality the picture remained rather different. There was still a greater

role for professionals, such as GPs, to actually take such decisions, acting as users' "agents" and very limited opportunities for individuals to themselves act as consumers. The transfer of this model from the world of commerce to that of welfare was never going to be unproblematic, for care is not a commodity, nor are the recipients of welfare services equipped, like supermarket shoppers, with the powers and resources to voluntarily partake of them. Nor were these services ever provided on a straightforward supermarket model to meet consumer need freed from political and value judgments, rather they always had their roots in the state's need to regulate, control and punish, as well as to help, support and care for, its citizens. Their antecedents in the Victorian Poor Laws, with their notion of the distinction between the deserving and undeserving poor, remain. In addition, the context for the implementation of even this model of user involvement was far from propitious. Set against a background of financial and political retrenchment and a government seen by many as committed to an attack upon the very foundations of the welfare state, there was always considerable distrust of, and cynicism about, the involvement offered.

Consequently this period also saw the continued development of grass roots pressure for different kinds of services and different kinds of involvement. The new social movements flourished and grew. Oliver has described them at this time as:

> consciously engaged in critical evaluation of capitalist society and in the creation of alternative models of social organisation at local, national and international levels, as well as trying to reconstruct the world ideologically and to create alternative forms of service provision (Oliver 1990).

The model of involvement underpinning these movements within the fields of health and social services has been described as a democratic or empowerment approach, based on the concept of citizenship (Croft & Beresford 1992). This model is user, not management, led and starts from people's concerns about their lives in general, rather than their views on a particular service. It sees users as citizens entitled to be involved in the decision making process and aims to gain for them real power to influence and change the services on offer (Croft & Beresford 1993).

The growing interest in citizenship had aided the rise of various user groups during this period. Encouraged by the growth and success of disability rights groups in America, Italy, The Netherlands and elsewhere, new groups were rapidly forming, organising and campaigning in the UK also. 1981 had been designated as the International Year of Disabled People. In

Britain it was marked with the formation of the British Council of Organisations of Disabled People [BCODP] Its title is important, for it marks the now clear, grassroots awareness of a need to distinguish between organisations of disabled people and those run for them by non-disabled people. By establishing a strong network and support system for such groups BCODP was able to work on developing an alternative theoretical model of disability and disabled people; a social model which located the "problem" not in individual people with impairments but in society's response to them (Oliver 1990).

For users of mental health services there are particular problems and tensions with both the models of involvement discussed in this section. They still faced huge cultural obstacles before they could hope to be generally viewed as having the mental capacity or economic resources to act as consumers or the same rights of citizenship as people with physical impairments. The mental health user movement has never been clearly allied with the wider disability movement nor succeeded in developing a coherent, alternative model of mental distress. Nevertheless, the users of mental health services did begin to find an outlet for their dissatisfaction during this period, both through the growing strength of MIND and through the user-only group Survivors Speak Out, which was formed in 1986 (Taylor, Hoyes, Lart & Means 1992).

4.3 1990–96: The "new" community care and associated developments in mental health policy

The ideas set out in the 1989 White Paper "Caring for People" [discussed in Chapter Three, section 6.3.] were for the development of "community care in the next decade and beyond". The long time scale was an acknowledgment of the scale of change that would be involved in implementing this latest vision of community care. As earlier chapters of this thesis have shown, community care had by this time become a policy which successive governments wished to see applied to meeting the needs of a range of client groups, not just people with mental health needs. Its stated aim was to achieve improved outcomes and a better quality of life for people requiring long-term care, through the provision of user-centred services that promoted choice and independence. Consequently, given this overt focus upon the needs and outcomes of all its service users, this might be seen as a golden opportunity for service users to develop new and improved services and relationships with professionals. In reality however, this White Paper was, like all others, a political document and the result of many competing agendas and demands.

From the very moment when it first appeared it received a mixed reception, for there had long been widespread doubt about any government's real commitment to, or understanding of, community care. Commentators immediately described local authorities as being handed a "poisoned chalice" of new responsibilities without the resources to discharge them. For many months, if not years, many people remained unconvinced that the policy would be implemented at all. They were therefore reluctant to commit time, energy or resources to it in the face of so many other competing and clearer demands.

Nevertheless, as Wistow has pointed out:

> in a field of implementation notorious for muddle, contradictions and ambiguities, the White Paper was intended to provide a coherent framework of ends and means to shape the development of community care over the next decade and beyond (Wistow 1995*a*).

By stating what the government now saw as being the aims, objectives and components of community care [para. 1.8.] it laid down the template for its future development. However, like all policies, it was not to be implemented in a vacuum but rather had to compete with many other social policy initiatives.

In a pattern now so familiar from earlier chapters of this thesis, the publishing of the White Paper and of the subsequent NHS and Community Care Act in 1990 was followed by a series of policy documents and statements.

4.3.1 The new community care

Although full implementation of the Act was almost immediately deferred by two years [April 1993 rather than 1991], the Department of Health did institute a programme of development work, covering what needed to be done and how, as well as the arrangements for its monitoring by a joint NHS Management Executive and Social Services Inspectorate team. The first guidance appeared in 1991 and covered inspection, purchasing and assessment, and Care Management.

In 1992 the Foster/ Laming letters of March and September identified the main requirements upon health authorities and social service departments at this stage of the implementation. They were to assess and arrange appropriate care for new clients who would previously have been supported through the social security system. The NHSME further identified eight key tasks for this that must be undertaken before full implementation on 1st April 1993.

As these were going to be the areas monitored by the joint teams they naturally received the most attention and were areas concerned with the care of older people particularly.

The Audit Commission, with a long history of interest in the implementation of community care, published two reports in 1992. The first "Community Care; managing the cascade of change" gave an overview of the policy and focused on interagency aspects of community care.

The second "The Community Revolution: personal social services and community care", reviewed the arrangements for implementing community care by highlighting the problems facing social service departments in rising to the policy's challenges to its traditional ways of delivering care. It pointed out that the departments were also having to grapple with the requirements of 1989 Children Act and 1991 Criminal Justice Act and that the concurrent changes in the NHS were leading to an expansion of community-based treatment and support, whilst the transfer of social security funds in 1993 would occasion an increase in demand for services. It acknowledged that it would be difficult for the authorities to know where to start in the midst of such substantial changes on such a large numbers of fronts simultaneously.

The report identified three major obstacles facing social services departments: a resistance to change; inadequate systems; and a fragmented service, particularly between social services and health. In order to overcome these obstacles the departments would need to undergo a "cultural revolution" in order to turn a service-driven organisation into one that was focused on the needs of individuals. To support this changed way of working it would need improvements in its information and system requirements and in its co-operation with the other agencies involved in community care as well as with service users.

The preface to the report stated:

> The delivery of care and support to adults in the community will undergo a fundamental change in the 1990s....Behind these changes are two key aims from which the others flow. The first aim is to empower the service users and their carers giving them choices about the support provided so that their needs can be met in ways and at times convenient to them. The second is to enable people to be cared for in their own homes where appropriate, rather than in residential settings simply because that is where the resources lie. In addition, where more than one agency is involved in arranging for care to be delivered –e.g. social services and health authorities– then service delivery should be co-ordinated so that the users and their carers experience a

> "seamless service."
>
> To implement the new legislation and deliver these objectives a revolution must take place over the next decade in the way social services operate (Audit Commission 1992).

By 1995 a document issued by the Department of Health "Building Partnerships for Success" felt able to claim "most important of all, the reforms changed the relationship between local authorities and users and carers" (Department of Health 1995*b*).

4.3.2 Mental health services

Two initiatives specific to mental health were introduced in 1991. The first, the Care Programme Approach [CPA] was mainly an issue for the health service. It was intended to provide a framework for the provision of community care for people with mental health problems by requiring health authorities, in association with social services departments, to set up individually tailored care programmes which identified the health and social care needs of all in-patients about to be discharged from psychiatric hospitals and all new patients accepted by specialist psychiatric services. Each person was to be allocated a Key Worker to co-ordinate and review the delivery of this care plan (Department of Health 1990). CPA has its roots in the 1975 White Paper "Better Services for the Mentally Ill" and in the sections of the 1989 White Paper which discussed public and professional concerns about maintaining contact with people being treated in the community. Its stated objective is to ensure that people do not "slip through the care net". Is this a threat or a promise? A vision of support or entrapment? Once again the twin concerns of community integration and individual autonomy on the one hand and of continuing surveillance and supervision on the other collide.

The implementation of CPA across the country was slow and patchy. In large part this was because those charged with its implementation were themselves unclear about it. In particular there was confusion about the ways, if any, in which it was intended to be linked with the concurrent development of care management, which was itself still an unclear process and role. There were obvious overlaps between the two in areas such as assessment, care planning, and the appointment of a key worker but also important differences which stood in the way of a simple conflation of the two.

The second initiative of 1991 was the implementation of the Mental Illness Specific Grant [MISG]. It was mainly an issue for social services departments. It was introduced to:

> reinforce the policy established in 1975 with "Better Services for the Mentally Ill", and to carry forward the objectives of the community care White Paper "Caring for People"; that is, to develop a comprehensive network of health and social care facilities to enable people with mental illness to be cared for, and treated, locally in the community. The purpose of MISG was to improve and expand social care services for people with mental health problems (Department of Health 1995*a*)

MISG was a revenue grant of 21 million pounds in this first year, paid to local authorities, who had to contribute 30 percent. It was ring fenced for three years for spending on new social care facilities for people with mental illnesses. This was an acknowledgement of the problems caused by the lack of development of such facilities as part of community care provision. The MISG aimed to clarify where the responsibility lay for such developments, provide the resources for them and increase social service spending on mental health and the amount of inter-agency working. It was intended to be closely linked with the CPA in that it could provide the resources to support the care plans. In 1992 the grant was increased to 31.4 million pounds and the ring fencing extended by a further year. It was further extended in later years.

Whilst the extra money provided by the MISG was very welcome, studies undertaken to monitor its use soon found that it was being employed mainly in a short-term, fire-fighting capacity, to plug gaps in the system rather than to support longer-term, strategic planning, as intended (Department of Health 1995*a*).

A White Paper "The Health of the Nation: a strategy for health in England", was published in July 1992. It highlighted five key areas for action, of which mental illness was one. It set national objectives and targets for each key area and outlined a strategy to achieve them. The three targets for mental illness were: to significantly improve the health and social functioning of mentally ill people; to reduce the overall suicide rate by at least fifteen percent by the year 2000 [from 11.1 per 100,000 population in 1990 to no more than 9.4]; and to reduce the suicide rate of severely mentally ill people by at least thirty-three percent by the year 2000 [from the estimate of fifteen percent in 1990 to no more than ten percent] (Department of Health 1992).

The government identified improved supervision of patients' care in the community, through the CPA, as one element in the strategy to achieve these targets, alongside improvements in information and understanding, the development of comprehensive local services and support for the development of good practice. A Mental Health Task Force was established to help guide

the development of these comprehensive local mental health services.

In January 1993, as part of the Health of the Nation strategy, the Department of Health issued the Key Area Handbook on Mental illness. It was designed to help local managers in health and social services develop their own local strategies. The handbook claimed that:

> major advances have been made in the last decade both in the understanding and management of mental illness and the risk factors and circumstances in which suicide occurs. Significant opportunities now exist for the effective treatment and continuing care of people with acute and severe and enduring mental illness and the reduction of suicide rates.... In spite of the opportunities provided by these developments, mental illness has remained a poor relation in NHS and LA management priorities. Services have been fragmented and poorly co-ordinated, resulting in poor information and inappropriately targeted resources; alliances between health and social services have not been developed to their full potential. [paras. 1.6-7.] (Department of Health 1993*b*).

In August 1993, in response to public concern over a number of high-profile homicides and suicides committed by people with a history of mental health problems, the Department of Health issued a 10 point plan to aid the development of "safe and effective community care for mentally ill people". It focused on the arrangements for the "supervised discharge" of people detained under the Mental Health Act. This would result in the implementation of supervision registers and further guidance on discharge in 1994, and the Mental Health [Patients in the Community] Bill in 1996, which introduced supervised discharge for some patients.

In November 1993 the Department of Health published the results of its brief examination of the implementation of community care for mental health service users. The study found a great deal of activity and many examples of good practice. However, it went on to state that:

> development is patchy and although the "what is to be done" is becoming clearer, the "how" is still confused. Plans have often lacked a strategic approach, resources remain insecure and the new mechanisms set up to improve care and support in the community for people with mental health problems overlap (Department of Health 1993*a*).

In 1994 the Mental Health Foundation published the results of its own inquiry into community care for people with severe mental illness. It stated:

> our vision starts with the clear premise that good community care for people with severe mental illness should be built around their needs, to enable them to lead full lives within ordinary local areas. For understandable reasons, a concern to respond to public fears about the few who may cause harm to themselves or to others has dominated the community care agenda, resulting in a loss of attention to the issues which should form its primary focus. We feel strongly that it is time to redress the balance and develop community care policies and practices designed, first and foremost, around the needs of the majority of people with severe mental illness who do not constitute a risk to the public [chapter two].
>
> Our vision is, regrettably, some way from being achieved. This is not for any single or simple reason. There is no comprehensive strategy from government for people with severe mental illness, insufficient resources, diffused responsibility, lack of understanding of severe mental illness and enormous pressures of organisational change [chapter three] (Mental Health Foundation 1994).

In 1994 the Audit Commission published a report entitled "Finding a Place: a review of mental health services for adults". It identified a number of familiar problems with the implementation of community based mental health services, including the lack of a clear strategic approach, the patchy implementation of CPA, poor co-ordination of services and a mismatch of needs and resources. It recommended that resources be targeted on those who are most severely ill (Audit Commission 1994).

Health service guidelines published in 1994 decreed that there must be an independent inquiry and published report available to the public whenever there was a homicide involving previous contact with the specialist mental health services. Seven reports were published in 1995: another seven in 1996. Their findings and recommendations were studied in a publication by the Zito Trust which was scathing in its appraisal of community mental health services:

> These services clearly lack the basic requirements: the finance, planning, training, supervision and the right tools for the job....The failure of the policy in so many cases is a damning reflection of the almost complete absence of any strategic planning....One of the baselines for the consistent delivery of these therapeutic services across the care range is pro-active and efficient communication between all the agencies involved. Or, indeed, any communication (Sheppard 1996).

However, the message most clearly picked out by politicians and the media from these reports concerned not these failings in the mental health system but failings in people with mental health problems which made them a potential danger to all. was not

The Department of Health did address some of these continuing criticisms of the lack of any clear lines of responsibility or of co-ordination of care in the 1996 document "Building Bridges" which was sub-titled "a guide to arrangements for inter-agency working for the care and protection of severely mentally ill people." The foreword stated that its aim was "to ensure....vulnerable patients do not fall victim to gaps in service provision" (Department of Health 1996). However its answer to these problems lay in greater supervision of those considered most at risk through the provision of 24 hour nursed care, crisis services and supervised discharge.

4.3.3 Successes and problems

The 1989 White Paper and subsequent guidance ensured that the broad thrust of government policy and thinking on community care was clear. Care was to move from institutional to domiciliary settings, from the NHS to local authority jurisdiction, from mainly public sector provision to a mixed economy of care, from service-led to needs-led provision. The aim of the new community care was to provide services to fit their users' needs. Local authorities would take the lead on this and achieve it through assessing individual needs and devising care packages to meet them that would provide high quality and cost effective services that maximised service users' choice and independence.

However the thinking behind this general thrust had been heavily influenced by, and thus bore the imprint of, some key lobbyists such as the owners of independent care homes, those concerned with the care of older people, and those concerned with capping the social security budget. Once again the particular needs and concerns of people with mental illnesses were subsumed beneath these more powerful agendas.

The new community care's underlying values and principles of ordinary living, personal development and independence were generally supported but, as Wistow has pointed out the new policy was "ambitious, complex and largely untested. Therefore its implementation was always going to be technically difficult and politically risky" (Wistow 1995*a*)

Its implementation was set out in the copious guidance as a series of logical steps. However actually implementing it in the country's many different local contexts, cultures and histories, and at the same time as so many other policy changes was never going to be either simple or logical.

As always in the community care story, its implementation was bedevilled by a lack of understanding, particularly of the concept of care management, its functions and tasks, and the role of the care manager. Given the variety of interpretations that developed even within social service departments, it was unlikely that shared meanings could be developed within and between agencies as planned in the guidance (Lewis, Bernstock & Bovell 1995). In addition, it was not clear how the care management systems would then fit with commissioning strategies.

Many commentators have pointed to the continuing and new dilemmas and tensions in this new community care policy. The main tension stems from the policy's own central concept, that of service users' needs, and is thus very important to the development of this thesis. The concept of need is yet another that has never been clear but always contested. The Act had placed a duty upon local authorities to assess individual need, but left them to decide whether and how to then meet it. It also did not differentiate between the needs of users and of carers, nor make it plain whether users and carers would define their own needs or whether professionals would do it for them within their own frameworks of risk, dependency and statutory duty. Even if these difficult conceptual and practical hurdles could be overcome, many more loomed ahead for, although the policy stressed the importance of meeting individual need and choice, local authorities would have to do so in a context of very limited resources and strict rationing of services.

Although it is this area of the policy that is of most concern for this study, both Lewis and Wistow have highlighted the many tensions within as well as between all six key objectives of the new policy (Wistow 1995*a*) (Lewis et al. 1995) Naturally these influenced and confused the staff charged with implementing it. Wistow has described these problems as "deep contradictions in the policy as a whole, rather than initial teething troubles" (Wistow 1995*a*).

Given the long timescale of the changes and their delayed implementation, 1996 was perhaps too early to judge whether or not they were successful. That success is itself dependent upon which criteria are employed and from whose viewpoint. Various studies have shown that these early years of the policy were viewed by many staff as a success in that, although they were difficult and stressful times for them, the predicted disasters did not take place and the necessary systems and procedures were established. Service users and their carers however saw little change in either their practical situation or in style of their relationships with professionals (Henwood, Wistow & Robinson 1996).

The changes being implemented within the health service also had important implications for the new community care in general and for mental health service users in particular. There was increasing pressure upon acute hospi-

tals to treat larger numbers of people and to discharge them more quicker. Achieving the targets set for the reduction of waiting list numbers was a high priority. This meant an emphasis on acute, not chronic, illness and care and, when the imperatives of those two concerns collided, an emphasis upon the hospital discharge procedures for older people rather than the repercussions for any of the other community care groups.

The old tensions and dilemmas of uncertain objectives, limited resources and a lack of clear commitment and direction at all levels seemed set fair to continue under the new dispensation, leaving all service users, but particularly those in mental health, once again lost in the spaces between rhetoric and reality.

4.4 Involving and empowering service users

This chapter has shown that social policy documents had given increasing emphasis to the importance of involving and empowering service users and their carers. The new community care and health services were not to be just the same services but in different locations, rather they were to be culturally different in that they were to be driven by service users' and carers' needs. The 1991 guidance explicitly stated that "the rationale for this reorganisation is the empowerment of users and carers" [p.7.] and drew attention to "the commitment to ensure that all users and carers enjoy the same rights of citizenship as everyone else in the community" [p.21]. The titles chosen for early documents continued to reflect this, for example "Putting People First" (Department of Health 1993*b*), "From Margin to Mainstream: user and carer involvement in community care" (Goss & Miller 1995) and "Working in Partnership: a collaborative approach to care" (Department of Health 1994).

However, like so many of the key terms in current social policy, notably "community" and "care", these too are something of a catch-all, meaning everything and nothing. The terms used, involvement, empowerment, participation, are very broad and often employed as if they were simply interchangeable and in ways which contributed to the confusion in the debate and dismay in people's interactions with professionals.

Involvement has often been portrayed as a ladder with several rungs or layers (Croft & Beresford 1993). Thus it can be visualised as ranging from, at its lowest level, a one-way flow of information from the authorities aimed at gaining support for existing services, right through to, at its topmost height, full user control of service planning and delivery. The lowest rungs are characterised by this one-way flow of information and are often described as non-participative. The next levels include information exchange about

agencies' plans and consultation. They are used to inform, persuade and explain decisions taken by professionals who still hold all the power and were the most common forms of user involvement in the health and social services in the early 1990s. The rungs above these involve the development of genuine partnerships between service users and professionals, with two way flows of information and dialogue and some delegation of power from professionals to users, allowing them to be actively involved in making decisions that lead to change. The final rung passes control over services to users.

The "ladder" thus portrays the power sharing elements of various types of service user involvement, the "what's on offer". The other necessary element is the "who's involved", that is whether individuals, groups, particular organisations or the public at large. The level of involvement, the people able to be involved, and the aims of the involvement all need to be made clear.

Much of the health service guidance from this period is concerned with consultation, which lies on the middle rungs of involvement and can be used in a variety of ways. At its lowest level, it is merely tokenistic and used to enhance decisions already made by professionals or to shift responsibility for unpopular rationing decisions. It is seen as a one-off event that must be seen to be done in order to comply with regulations. At best, it reflects a genuine desire to establish effective communication with service users and carers or the public and is an on-going process. The 1990 NHSME Guidance on involving the consumer states "the essence of consultation is the communication of a genuine invitation to give advice and a genuine receipt of that advice" (NHSME 1990). However, another continuing theme of this thesis is the gap between rhetoric and reality, between theory and practice. Given the wider social and economic context in which such involvement and consultation took place, with staff fearful for their jobs and people aware of rationing of services and strict limits on resources, both were likely to be feeling vulnerable and confused. The scale of change taking place in so many areas added to this and often left people feeling cynical about the involvement on offer and perceiving not a widening of choice and independence but rather continuing cutbacks in services and a growing feeling of powerlessness (Croft & Beresford 1992).

By 1993 the term "partnership" was becoming increasingly popular in health and social service documents, depicting a cosy image of service users and professionals eagerly working together towards shared objectives. Again the reality was often very different. Given the conditions under which staff and service users meet, at times of crisis and despair and through problems and impairments which are stigmatising, and with important differences in age, class and ethnic origin, it is hard to establish an equal partnership.

The guidance which underpins this model of involvement is usually based upon a consumerist model which is not applicable to many community care services or its users. Whilst such a model may be useful as a theoretical model to shape future development, to translate it from words into action would involve a major cultural transformation for both service users and professionals.

Various forms of advocacy had also been developing during this period and some authorities had taken the setting up of an advocacy project to be a proxy for their successful commitment to involving service users. However, although an advocacy project may facilitate that, the two things are not the same. Advocacy is a tool or instrument to be used on the road to service user involvement but cannot, on its own, guarantee it (Brandon & Brandon 1995).

Whilst many of the terms considered so far can be described as involving service users, very few are empowering. Empowerment is yet another contested term and one again ever more frequently used and often taken to be synonymous with involvement (Servian 1996). However, few schemes for service user involvement have yet developed beyond the stage of consultation, where professionals still hold all the power. To progress further up the ladder of involvement and into the realms of empowerment is very challenging, since it must involve radical changes in staff attitudes and practice at all levels and in organisational structures. Service user involvement is often still an "add-on" to an agency's traditional ways of working. With empowerment such an arrangement is not possible. Empowerment is central or not at all.

Much work has been undertaken across a variety of disciplines in the study of empowerment. It has been described as both a process which entails working with, listening to and respecting service users and sharing power with them, and as a goal achieved when individual service users feel themselves to have more control over their lives and over the care and support they receive and the power to exert control over others. However most studies show that empowerment in the context of community care is still poorly theorised and understood. As Servian says:

> the findings show a picture of contradictions and tensions in power relations between carers, users, workers and managers. A suggestion is that, despite policy changes, historical power relations are reproducing themselves and users continue to be disempowered (Servian 1996).

Many commentators have developed models delineating approaches to empowerment within two broad schools; consumerist or democratic. Consumerist approaches grant power to service users through the possibility of "exit" [moving to a different provider]; through choice between providers; and

through procedural rights [citizens charter, inspections, complaints]. Democratic approaches grant power to service users through "voice" [having a say in decision-making and planning]; through developing their confidence in the services and trust in relationships; and through substantive rights (Croft & Beresford 1992) (Hoyes, Jeffers, Lart, Means & Taylor 1993) (Barnes & Prior 1995). The democratic approach would therefore seem to have most relevance to the users of mental health services, but it has largely been the consumerist model to which the government has subscribed.

In addition, just as with care management, there remain large differences between health and social services in terms of their separate visions of involving users and carers. These are largely inherited from their different histories and cultures, but now have to merge, or collide, in their planned joint working.

The Department of Health set out its central vision in a 1995 document entitled "Building Partnerships for Success".

> We want to see the relationships between users and carers and the various authorities and agencies on whom they depend develop and mature into a more genuine partnership. Improving the quality of life of users and carers, improving the outcomes of what we are doing, MUST involve empowering users and carers; listening to what they really want, taking note of what they say; involving them in decision making at both a personal and a strategic level (Department of Health 1995*b*).

Once again, implementing this vision has been devilled by a lack of clarity for all and at all levels as to quite what is on offer, to whom and to what end. The idea of involving users and carers is confused conceptually, in policy and practice. Consequently both the debate and the development are hesitant and cautious. Much of what is done consists of re-inventing the wheel, not least because those involved in practice have neither the time energy or funding to write up and disseminate their findings. Beyond this, even what is achieved tends to mirror, rather than challenge, existing discrimination and oppression, giving voice and power mostly to White, middle-aged, middle-class, men and supporting them in taking on provider and professional perspectives (Croft & Beresford 1992) (Barnes & Wistow 1992). For real progress to be made, the issues must be clarified and involving service users be truly placed at the heart of service delivery. Once involving service users was a central activity and way of thinking, rather than one tacked on to the end, or hived off as a discrete activity that one or two people are responsible for, with uncertain resources and no long term planning, the result would be a very different style of service.

The difficulties that arise from the lack of clarity about the process of involving and empowering service users is further compounded by differing, but often unvoiced, conceptions of who the service user is and what his/ her characteristics are presupposed to be.

At its simplest, this may revolve around deciding how much of a service one has to use in order to qualify. Would one GP or out-patient consultation count? Do people have to have been in contact with services for a certain amount of time? Or have experienced particular treatments or symptoms? Does the term include only those currently using services, or also ex-users/ potential users/ dissatisfied users? What about excluded users and those with currently unmet needs, who may be further disempowered if involvement is only for those already using a service? Where there is felt to be some stigma attached to being a service user, people may be reluctant to be identified as such. Service users may thus face emotional and psychological, as well as financial, implications from agreeing to be involved (Hoyes et al. 1993).

Even when people have been identified as service users, whether by themselves or by professionals, there are still uncertainties to be resolved. "Service user" is another broad term that conceals beneath it a wealth of different images, quite apart from the obvious fact that all people are different. Quite how, and by whom, service users are defined will, in itself, have important consequences for what they expect of involvement and what others expect of them.

One image is of service users as patients. In this, mainly health service, manifestation they are the largely passive objects of the clinical gaze, set within a medical framework and inevitably dependent on the expertise of professionals. Service users as simply the recipients of services is another passive image that fails to capture their own active part in both producing and consuming services.

The manifestation most often employed within social services is of service users as clients. This term was imported from the private sector, where the client hires the expertise of a particular professional and both then share knowledge, information, records and decision making. Since the 1970s this model has been held up as the ideal to guide relationships in social work but has proved difficult to implement within areas like mental health services where those using the services often feel themselves to be in crisis, excluded from social life and routinely disempowered.

The ideal employed for service managers is now often that of service users as customers or consumers. Again it was introduced from the private sector and implies that service users are able to be actively involved in making choices between services and providers. In practice this model does not fit, since in health and social services, users do not have direct control over

resources but rather professionals, such as GPs, health authorities and care managers, continue to make these consumer choices on their behalf. Service users, especially in mental health, are left without the choices, power and voluntary use that these terms imply.

When the statutory agencies seek to involve service users they often turn to local voluntary organisations and user groups. However these too cover a wide range of models and ideologies, depending for example on whether it is an organisation of or for disabled people. Some authorities are still content to use staff views, particularly those of GPs, care managers and nurses, as a proxy for service users' views. They are assumed to be able to act as service users' advocates but this assumption ignores their potential conflicts of interest and the power differential between staff and service users. Finally, service users' and carers' views are sometimes conflated into one, or it is again assumed that carers can always speak for service users. These assumptions do not make due allowance for the complex nature of the relationships between service users and their carers and the fact that carers can also be service users. In addition, many people do not have a carer nor would they wish to be seen as in need of one.

The term "survivor" has been adopted by some mental health service users because they feel that it more accurately reflects their experience. It expresses their dissatisfaction with the services they have experienced and is often coupled with a rejection of a narrowly medical model of mental distress. They feel that the term service user implies an active decision to use services which is not available to many people with mental health problems who have always the threat of compulsory treatment before them.

Because the concepts and processes of involving and empowering service users are still in their infancy the language in which they should be described is also hotly disputed. Many aspects are still dominated by the language and agendas of professionals, with service users left feeling that they have to learn this language and react to these agendas even if they do not fit easily with their experiences and concerns. Many of the terms and categories currently being used need to be "unpicked" and the images of service users unravelled.

4.5 Where were mental health service users by the mid 1990s?

The mental health service user movement had continued to develop and was well established throughout the country, but had not made any clear links with other disability groups nor developed a shared alternative model of men-

tal distress around which to build campaigning activities. Some groups were active in providing services, some in planning them. Some groups worked with mental health professionals, some wished to remain separate. Consequently the "movement" remained fragmented and some groups were perceived as being in competition with others (Rogers & Pilgrim 1991) (Barnes 1997). Nevertheless the activities of groups such as Survivors Speak Out, The United Kingdom Advocacy Network [UKAN] and Mindlink were influential in shaping the language and thinking of at least some professionals, politicians and service users. This influence then gradually filtered through to others. In addition, Barnes and Shardlow have argued that participating in mental health service user groups is in itself transformative for both users and professionals, since such participation challenges professional stereotypes and enhances the construction of service users as active citizens (Barnes 1997). The re-wakening of interest in the concept of citizenship was starting to spread to include mental health service users, although there was also a growing awareness of the problematic nature of the concept as currently defined and subsequent calls for its re-definition in the light of the experiences of women, disabled people, and those from minority ethnic groups.

Certainly the practice of involving mental health service users in planning both their own care and wider services had become much more widely accepted, although such involvement was usually limited to the lower rungs of the "involvement ladder".

Many service users were still not involved with any mental health groups and remained unaware of these wider debates taking place on their behalf.

In the light of the various developments and debates examined in chapters two, three and four of this thesis, it is clear that, once again, there are no simple answers to the question posed in this section. In some ways, some mental health service users had made considerable progress in setting out new conceptualisations of themselves and their experience. These have very important implications for the kinds of relationships which service users can have with professionals and, therefore, for the kinds of services which are provided. Since in all relationships "what you see is what you hear", changing conceptualisations lead on to changes in what professionals hear from service users and in how seriously they take what they hear.

At the same time, many other mental health service users were continuing to describe their situation and experience in ways that seemed not to have changed at all:

> Within the mental health enterprise it largely remains the case that people who experience mental distress and disability are very much second-class citizens. It is not possible for service providers

> to involve or work alongside the users of their services unless they value them. Value not simply those aspects of a person that are unrelated to their mental health problems, but also the expertise which madness itself affords (Perkins 1996*a*).

Certainly mental health service users continued to face particular difficulties in knowing where they both were and should be. In terms of their social, moral and economic "spaces", they were once again lost, as with the physical spaces, in the confusing gap between rhetoric and reality. In attempts to position themselves as citizens they were at a disadvantage because so many of their rights were threatened by their diagnosis. In attempts to position themselves as consumers they were at a disadvantage because they were often still presumed to lack insight into their own condition and needs. Within the health and social services they were often lost beneath the more pressing imperatives of acute hospital services or of the care of children and older people. Even within mental health services, service users with severe and enduring mental health problems were lost between the demands of the "worried well" and of those deemed to be dangerous.

5. HEARING VOICES: THE RESEARCH APPROACH AND PROCESS

5.1 Introduction

" Felix qui potuit rerum cognoscere causas.

[Fortunate indeed is the person who has been able to understand the causes of things]

Virgil, Georgics, Book 2, line 490. 22 B.C. "

The previous chapters of this thesis have outlined and discussed the history and development of mental health services in Britain and, in so doing, have shown that mental illness has long been, and remains, a contested concept. Nevertheless, large numbers of people continue to be categorised as suffering from it and it was consequently highlighted as one of the five key areas for action in the 1992 Health of the Nation strategy document (Department of Health 1992), which acknowledged the urgent need for more information about, and understanding of the nature of mental illness and the needs of those who live with it.

Throughout the historical period covered by this thesis, although various policies with respect to mental illness have come and gone, certain themes and concerns have remained remarkably persistent. At root, these are based in our society's continuing uncertainty about the nature of mental distress, about the best response to it, at an individual or societal level, and about the kinds of relationships deemed appropriate with those who suffer from it: the differing nature of these over time revealing as much about the society of the day as about the nature of mental illness.

Mental health policy has, consequently, always reflected these uncertainties and so contained within itself conflicting and contradictory messages, both for the public at large and for people with mental health problems in particular. Throughout the centuries, it has remained a highly controversial policy arena.

The shift in the location of support for people with severe and enduring mental health problems, from one institutional base to a variety of community bases, has still left mental health service users in very uncertain spaces and relationships [it may, indeed, have exacerbated the situation] and at the epicentre of a heated social policy debate.

Despite being placed in the centre of this debate, the voices and experiences generally missing from it are still those of mental health service users themselves. In the past there was no acknowledgement of any necessity to include them. In recent years, as the discussion in Chapter 4 has shown, that has changed, giving rise to a stream of policy and practice guidance encouraging the inclusion of service users in service planning, delivery, monitoring and evaluation, and research. Yet still their understanding of their experience has been largely excluded. This is particularly the case for people with severe and enduring mental health problems, who are the focus of this study. They are often portrayed as unable, by the very nature of their illness, to offer rational and valid opinions (Rose, Ford, Lindley & Gawith 1998) (Rogers, Pilgrim & Lacey 1993).

This chapter begins by outlining the history of social research [section 2] as part of the necessary background to, and locating of, this study's particular approach to its research problem. An understanding of the history of social research is important in order to understand the nature and standing of the various methods, and their philosophical underpinnings, that could have been chosen to investigate this area.

Section 3 describes the decisions made regarding the most appropriate ways in which to seek to achieve the project's aims. The methods chosen from the menu available at any particular time have a crucial impact on the outcomes of any study, for methods and findings are inextricably linked. All methods and approaches in social research have their own problems and challenges. Therefore, researchers need to constantly review their own practice, and that of other researchers in the field, in order to learn from their practical application and it is often the case that one learns to what extent particular methods will achieve the desired aim only by trying them out; perhaps never more so than during the course of a Ph.D., which is itself a learning process, an apprenticeship in the art of social science.

All decisions regarding the conduct of social research are, knowingly or unknowingly, underpinned by particular philosophical stances towards the nature of social reality and the ways in which it can be known. The ontological and epistemological stances adopted by the researcher inevitably both limit and, to some extent, predict the possible findings of each study. In the social sciences, these decisions and stances remain disputed and controversial.

Section 4 describes the ways in which the chosen methods were applied

throughout the research process and discusses the problems and successes encountered and the rethinking which this entailed.

Section 5 concludes the chapter by summing up the lessons learned regarding the application of these methods during this research study.

5.2 The research methods context

" The truth is rarely pure, and never simple.

Oscar Wilde, "The Importance of Being Earnest," "

During the relatively short history of social research, various methods and approaches have occupied a dominant position at various times and to various ends. Within the social sciences, these can be categorised as forming two main traditions, which each recommend very different approaches to social research.

Prior to the 1970s, the quantitative survey style of social research reigned supreme, not least because it was held to be closest to the presumed methods of natural or "hard" science. This style of social research was underpinned by an adherence to the metatheory of positivism and a belief that social science can, and should, be "scientific" in the same way as physics or chemistry. It was concerned with observing, charting and predicting an external social reality and, consequently, displayed a preference for numerical data, measurement and quantification.

However there were also other ideas developing during this time; a second tradition of interpretive social research, based around concerns over language and meaning in attempts to understand social actions (Davidson & Layder 1994). Particularly during the 1970s, the assumption that the natural science model is also appropriate for the social sciences was challenged, largely under the influence of ideas from phenomenologists such as Husserl, continental hermeneutic philosophers such as Heidegger and Gadamer and philosophers of language, such as Wittgenstein and Winch. When transferred to social research, their ideas brought into sharp focus the problems inherent in attempting to understand a social reality that is the product of its inhabitants and already interpreted and given meaning by them. In this scenario, social research needs rather to employ methods which give access to other people's internal subjective worlds. Thus these developments lent support to the claim that the social sciences need radically different, qualitative methods of research because of their radically different objects of study i.e. people not things, conscious actors not passive and unthinking objects, already pre-interpreted experiences not material items, and because of their

different aims, i.e. verstehen, an emphatic and interpretive understanding of other people's worlds, not general laws and predictions.

The debate over the relative merits of the various methods, and especially that between quantitative and qualitative approaches, became increasingly caught up in philosophical issues to the extent that the divide between the two came to signify not merely different technical decisions but a deeper divide about the very nature and purposes of social research: the methods adopted being taken to imply also a body of ontological and epistemological assumptions regarding the nature of social reality and how we may know it.

In part because of this background to its development, qualitative research can be difficult to define and is often described in terms of what it is not i.e. that it is not quantitative, not concerned with measurement, has an emphasis on understanding rather than explanation etc. Its aims are usually defined around a commitment to seeing through the eyes of those being studied (Bryman 1988). Consequently, its main methods are participant observation, unstructured interviewing and the collecting of life histories, since these are best suited to achieving this aim.

In more recent years any consensus as to what constitutes good social research has been further fragmented by developments in many different quarters. During the 1980s a large body of work emerged from researchers influenced by feminism (Harding 1986) (Stanley & Wise 1993) (Harding 1991) (Stanley 1990). Their far-ranging critique covered practical, ethical, political and epistemological issues, based upon the central tenet that the current, dominant approaches to social research were excluding the experiences of women and mistaking the unmarked subjectivity of white, Western, middle-class men for objectivity (Maynard & Purvis 1994). Through their efforts to open up the "silences" in both research practice and findings they revealed as problematic many areas previously taken for granted as good practice. As this work was further built upon, for instance by researchers interested in postmodernism and postcolonialism, the social sciences have had to face up to questions about how to access and represent other people's experiences, which are difficult both morally and epistemologically (Coffey, Holbrook & Atkinson 1996).

Amongst other things, this has entailed a re-thinking of the relationship between the researcher, those being researched and the knowledge produced. Using the methods of qualitative research, underpinned by an idealist ontology, where social reality is many faceted and changing, and an interpretivist epistemology, all data must be seen to be mediated by the thinking and meanings of both the researcher and those being researched. There can be no pure data, for the discovery of knowledge is not of something which exists "out there" but of something which is created by the interaction between

researcher and researched.

The re-examination of these research areas, alongside the blurring of many disciplinary boundaries within the human sciences, has also prompted a new interest in narrative. It has been increasingly recognised that we all use stories to fashion our very identities, to build up an autobiographical narrative which, in many senses, is our self (Kelly & Dickinson 1997). Storytelling is a universal human activity and one that we employ particularly at difficult times in our lives – to make sense to ourselves of breaches and traumas in our lives; to reconstruct a coherent self through these narratives. Consequently the telling of stories is likely to be very important in a study such as this one, which focuses on a chronic illness that causes a sense of biographical disruption to those who live with it. In addition, the joint production of interview data is now often seen to itself contain elements of narrative:

> The researcher and the researched are partners engaged in the act of storytelling (Sandelowski 1995).

Studies of the rhetorical language and markers of research reports have highlighted the storytelling element within them also.

Consequently, the debate regarding the methods that should be used to produce social scientific knowledge remains unresolved beyond the general agreement that such knowledge must be produced in rigorous, thoughtful and reflexive fashion, matching the research methods to the aims of the study, in order to attempt to formulate explanations and theories that are grounded in some form of empirical evidence.

5.3 The research approach

> *" And my methods? You asked about my methods? There are no secrets here. Like you, I read. I read continuously. I check my details, my dates, my facts. I do the spadework, the necessary research. But that is only the beginning, the preparation of the ground. The writing itself is of another order.*
>
> *Patricia Duncker, "Hallucinating Foucault", 1997. "*

Since this study's area of investigation is service users' experience of severe mental illness and of different patterns of mental health service delivery, and my own philosophical stance has a basis in an idealist ontology and an interpretivist epistemology, the most appropriate research approach would seem to be a non-standardised, qualitative approach. For this study is concerned with people's own perceptions of their lives and behaviours and aims to allow space

for their own accounts and stories (Strauss & Corbin 1990) (Fetterman 1989). Such an approach allows for the employment of a dialogic research process, which is the necessary context for the researcher to conjointly establish people's meanings and understandings (Lather 1991).

The study aims to explore and understand the nature of the local experience of receiving mental health services for severe mental illnesses in both institutional and community settings. Little is yet known about this and so the research requires an exploratory approach and access to the intricate details that give meaning, but are difficult to gather through quantitative methods. The study is concerned with processes and links, rather than single, observable experiences, and covers complex and sensitive issues. It therefore needs an interactive interview relationship and the opportunity for the progressive development of potential lines of enquiry.

The study is therefore based in, but is not a mechanistic follower of, the qualitative research method of grounded theory (Glaser & Strauss 1967). This employs procedures which are designed to develop an inductively derived, empirically grounded theory about a particular area of study. It does not start from an hypothesis which needs to be tested, as deductive work does, but rather from a defined area of study, with issues relevant to it allowed to emerge. It is therefore well suited to an exploratory piece of social research concerned with particular social actors' own understandings of their experience, since it begins with broad initial research questions, which are then progressively refined and developed during the research process. Indeed, the initial questions may do no more than state the phenomena to be studied; for example, what is the experience of severe mental illness from the perspective of adult service users in a particular location and in receipt of varying patterns of treatment and care?

This approach to social research is now well established and shown to be of value where a study aims to develop theory and increase understanding of particular processes through providing detailed descriptions of individuals' experiences in a local context and offering explanations of the meanings they attach to them. This approach should lead to the development of theory with "evocative power", that is theory that resonates with people's lived experience and which increases specificity at the contextual level in order to reveal how larger debates and changes are realised in the particulars of everyday life.

Its aim is to ensure that the theoretical categories and issues that become the central focus of the study are generated by engagement with the data. The use of this method ensures that any explanations offered by the study's findings are data-driven and grounded in people's own experiences, terms and meanings.

However, as Patricia Duncker points out, the writing about the research process is indeed "of another order." Traditionally research reports have adopted a clearly structured, linear form, wherein a clear-cut package of methods are adopted and their application distinguished from the findings of the study. In contrast, the Ph.D process covers many years, during which research ideas and methods develop and change as a result of experience and reflection and, in inductively derived, qualitative research, methods and findings are interlinked. Consequently the "story" of a qualitative Ph.D. is often more circular and episodic than linear and hard to present in the traditional format.

5.3.1 Generating and recording the data

> *" No-one means all he says, and yet very few say all they mean, for words are slippery and thought is viscous.*
>
> *Henry Brook Adams, "The Education of Henry Adams," 1907. "*

The central problem for a study such as this one is how, if at all, is it possible to access, understand and report other people's worlds and experiences? Social research has often, through different forms of interviewing, adopted the approach generally taken in the everyday world of one person asking another. This is not unproblematic, but nevertheless is the approach adopted here. Quantitative methods were unsuited to the aims of the study and participant observation would have been very difficult to undertake given the many different locations and settings in which people with severe mental illness are now living. Given the epistemological basis adopted by this study, it is recognised that language is not a transparent medium, which gives direct access to an unchanging and unitary external social reality. Rather, language itself helps to constitute that reality and interview data, like all data, must be interpreted against the context in which they are produced (Hammersley & Atkinson 1983).

This study will rely for its data on what people say in interviews, rather than on observation or documents, in the understanding that no data are "real" in the positivist sense i.e. as unchallengeable representations of an objective reality. Where the social world and representations of it are viewed as social constructs, no one view needs to be balanced by others or to have its true meaning revealed by outside experts. Instead, the data are needed to allow some interpretive access to respondents' self-reflexivity, feelings, identities and meanings: for it was their experience of self and the social processes that shaped that experience that came to be central to this study.

Modern sociology has been described as "the science of the interview" (Oakley 1993), yet the expression "a qualitative research interview" is one that badly needs unpicking. As Anne Oakley has pointed out,

> interviewing is rather like marriage: everybody knows what it is, an awful lot of people do it, and yet, behind each closed front door, there is a world of secrets (Oakley 1993).

Given the range of interactions covered by the term, it is important to adopt the one most in keeping with all the aims of the research.

In quantitative, or standardised qualitative research, the sample must be precisely defined and interview schedules agreed before any fieldwork commences, in order that those taking part provide a representative sample of the population under investigation and are all asked the same questions and in the same way. The resulting data are not analysed until all the questionnaires or interviews are completed. However, such an approach is not appropriate for this study, because it has different aims, which rather demand flexibility and variation in response to the different situations of those taking part; the researcher must be free to engage with each person directly and frequently in order to establish a dialogic research setting; and the data must be analysed while the processes of data generation are still ongoing, in order that emerging themes can be recognised, refined and developed in partnership with those people who are participating in the study. Formal interviews, conducted by a detached researcher through a structured schedule of pre-determined questions, are not suitable for generating data to increase understanding of the experiences of this group of people. Many will have experienced such interviewing frequently in a clinical, or other assessment setting and may therefore find it intimidating and with resonances that militate against the production of the kind of data needed for this study. In this case, the need to listen to individual experience is more urgent than the need to produce generalisable data (Harding 1991) (Oakley 1993) (May 1993). However, as Collins has pointed out (Collins 1998), the distinction between unstructured and structured interviews is often blurred. Interviewees will have their own understandings of the way in which research should be conducted and their own feelings about which approaches they feel most comfortable with. When researchers decide to undertake unstructured interviews they have taken an important decision, which will influence the possible outcomes of the research and whose voices can be heard in the end "research story".

Given my position on the nature of social reality and the best ways to know it, and the various aims of this study, I have followed Mishler (Mishler 1986) in regarding the research interview as a speech event, a form of "organised social discourse" rather than as an event within the behaviourist

paradigm, which views interview questions and answers as stimulus-response pairs. Adopting the "speech event" approach has major implications for the conduct and analysis of research interviews and, consequently, for their interpretation and writing up. It requires the researcher to take on the role of engaged and active listener and respondent, in order to establish a setting in which the researcher and the individual can conjointly produce the interview story and its agreed meanings through this particular type of conversation.

In such an interview setting, the researcher cannot simply assume a commonality of meaning, whether between individuals who take part in the study or between the researcher and a particular person. Instead the indexical nature of language must be kept in mind and attempts made to clarify the meaning intended by that person, at that time. In this way, the researcher and each individual together determine what is said in a research interview, and how. It follows from this that each interview is, and should be, a unique event. A different interaction would produce a different interview story. This is not to say that either would be untrue; merely that interview stories are, of necessity, constantly changing because people, situations and perceptions are constantly changing. You cannot conduct the same interview twice. Therefore the search for standardization in research interviews is misplaced, since it is the very flexibility and adaptability of the researcher that is the key to good interviewing.

In following this interview paradigm, the interview context therefore becomes of vital importance. If each interview is a unique and situated event, its data generated in a particular context, that context, which has two parts, must be made visible in order to explain and understand the data it produced. The two parts are the immediate physical context [where, when and how it took place, who was present etc.] and the larger historical and cultural context. The readers of research reports need an understanding of both contexts in order to be able to place the researcher's interpretations and to construct an alternative one of their own. In these interviews the contexts in which they take place, the discourses used and the meanings produced must inevitably remain intertwined. Within this paradigm, data are therefore generated, not collected (Morse 1994) (Mason 1996).

Such interviews aim to provide opportunities for people to bring forward their own concerns and meanings; to talk in their own terms and at their own time, rather than having to address categories already pre-defined by the researcher; to focus in depth on local issues; to capture the complexities and dynamics of individual's lives and experiences over time; to develop a relationship of trust and rapport with the researcher; to respond to a variety of situations and to allow for the joint discovery of the meanings that service users themselves attach to their experiences through further exploration and

development of the main emergent themes from each interview during the subsequent ones.

The interviews aimed to take a life history approach, since this has been shown to be an appropriate way to allow people to cover all the issues that seem important to them and in their own words, particularly in studies of people with chronic health problems. This approach can also capture the dynamics and complexity of long experience of, and contact with, the health and welfare services (Brown & Sparks 1989) (Thompson 1979). The people who took part in this study all had long experience of contact with the local mental health services. Adopting this approach meant that their present actions and feelings could be placed in the context of, and understanding of, their past experiences and present "patient career" stage.

By asking people to take part in a series of interviews, the study aimed to allow those taking part to consider and reflect on their experience and to contribute to the analysis of it in order to ensure that it captured their personal meanings and values. These kinds of linkages in the understanding of other people's experiences are often missed in research projects based on a "one-off" contact. This is particularly important now that patterns of health and welfare service delivery are changing from a single statutory provider into a variety of different agencies and settings: people may thus be experiencing complex and fragmented pathways through the mental health system.

When designed as an ongoing process, not a one-off event, the interviews allow the researcher a sustained period of contact with the people contributing to the study, and thus the time and space for each to develop some trust and rapport. They provide the flexibility for people to contribute when, and for as long as, they feel able to, i.e. to fit in with the patterns of their lives. They also allow their accounts to be checked, amended and added to in each interview, in the light of the concurrent analysis.

The interviews were designed to be guided and prompted by non-directive and exploratory questions from the researcher where necessary, but her open, attentive, careful and analytical listening was more important.

Despite being covered by one term, research interviews can, and do, include a range of data collection methods, which are bound to generate different types of data. These then need different types of analysis and reporting. Consequently, what happens, or does not, in interviews and the contexts in which they take place have huge implications for how much of whose story can appear in the research report. Researchers engaged in projects such as this one, which are ostensibly committed to reporting individuals' own views and perceptions, must therefore provide interview contexts and create interview interactions that encourage those taking part to guide the discussion and to develop their stories, explanations and meanings. The participants

must feel able to control the course of the interview. In a study such as this one, it is also vital that the research interviews enable narrative talk to occur.

However, the stories that we are able to fashion for ourselves at any one time are limited by the current stock of available general, cultural stories about that particular experience. Where, as in severe mental illness, the experience is negatively valued by society, it is difficult to talk about. People may feel silenced because their experience does not fit into the available cultural narratives and so there is no language for their experience. Therefore, one of the most crucial problems confronting the social sciences is how to represent such lives and experiences; how to translate between two such different social worlds in ways which remain meaningful to both. Indeed, if stories are so vital to the social scientific enterprise, how to make science out of stories (Josselson 1996) (Josselson & Lieblich 1995).

The stories that we tell are situated in a wider context –people's individual, social, historical and cultural lives. It is important to be aware of the cultural worlds of both the researcher and those being researched and of the current dominant, and competing narrative paradigms [in mental illness or social research], for our accounts are part of, and help to create the social worlds they describe: not only selves but also events are structured by our stories.

When research interviews are seen as speech events, where, in the course of the whole conversation, joint understandings and meanings –both cognitive and emotional– are established, then it is necessary to have as full a record of the whole interview as possible. It is never possible to capture the whole of the interview process, and a balance must be struck between fuller recording and people's feelings about destroying the trusting interview atmosphere. However, where people are willing and have given their informed consent, the interviews will yield greater depth when they are tape recorded. This has the added advantage of leaving the researcher free to concentrate on listening to and engaging with the participant, without the distraction, for either, of trying to simultaneously listen and write.

5.3.2 The sample and access

It was intended that the findings from this study should be ideographic i.e. that they should illuminate and specify the experience of a particular group of people. Although this means that the findings are narrow in focus, they compensate by providing greater penetration into the subject area than can the nomothetic findings produced by other styles of social research. They cannot, on their own, provide any claim to be representative of a wider population.

As the production of comparable or generalisable findings is not part of this study's aim, it was not necessary to select people to interview on the basis that they formed a representative portion of a larger population. They did, however, need to have shared the common experience of receiving mental health services in the area over a long period of time and it was desirable to select people from a range of backgrounds and situations. In particular, the study needed to include people with both the experience of a long in-patient stay in the psychiatric hospital and of a variety of community service settings. It is the events, incidents and experiences that are being sampled, not people per se, for the information they can provide about particular phenomena. Therefore those selected must have direct and personal knowledge of the topic of study that they are able and willing to communicate to others, and are only secondarily selected through age, sex, race etc. Primarily they are selected because they seem likely to be good sources of information that will advance the study's analytic goals, not because the aim is to generalise to others of similar age, sex, race etc.; i.e. a demographic variable becomes an analytic variable (Sandelowski 1995).

This type of sampling is known as purposeful or theoretical sampling, as opposed to the probability sampling of quantitative work. People are selected for inclusion in the study because they are able to offer in-depth information about typical, atypical, or exemplary situations. As the study progresses, people are selected to maximise theoretical development and/or provide data which might refute emerging hypotheses. Ideally sampling will stop when theoretical saturation is reached, i.e. no new insights arise from the data. Therefore, in these types of study, it is necessary to generate and analyse data and access people for the sample throughout the fieldwork period.

Consequently, determining the ideal sample size for research of this sort is very difficult. At root, the sample must be adequate to support the findings; that is, small enough to permit deep, case-oriented analysis and large enough to result in new and richly textured understandings of the experience under study: yet, the thrust of qualitative research work is case-oriented and too large a sample makes it impossible to complete detailed analyses of the data.

In addition, this study, like many, was limited by more pragmatic considerations such as its being undertaken by only one researcher with limited time. Since it was considered vital, in the light of the study's aims, to undertake repeat interviewing of each person, in-depth and at length, it was possible to have only a small sample

The avenues through which people are accessed also have implications for the conduct and findings of the research. These avenues are often far from clear-cut and may have to be negotiated and renegotiated as the research

progresses. Power and politics may limit or open up access and practical and pragmatic considerations may have to be balanced against the ideal situation. As Shaffir has acknowledged, access

> is far from being a straightforward procedure. It involves negotiation and renegotiation, influences the kind of investigation that can be completed and occurs throughout the research process (Shaffir & Stebbins 1991).

In a study such as this one, which is concerned with the experiences of people often considered to be vulnerable and whose experiences are in an area of high political sensitivity, ethical issues are likely to be raised by those who are in the position of gatekeepers and the value of seeking the views of people held to lack insight questioned.

In the light of these considerations, it was decided to seek access to people in the researcher's local area, where she already had some knowledge of the local situation, which would offer the necessary range of experiences, and where she was known to key personnel. Given the practical constraints and the aims of the project, it was thought likely that 20-25 people, with a wide range of experiences of severe mental illness within the county, would be included in the study.

5.3.3 Analysing the data

> *" In the social sciences, there is only interpretation (Denzin & Lincoln 1994). "*

In grounded theory studies, there is a reciprocal relationship between data and theory; the data are allowed to generate propositions in a dialectical manner, whilst keeping as open a frame of reference as possible i.e. being aware of relevant theories but not allowing them to constrain the development of possible new interpretations and findings. Therefore, the data should be extensively analysed immediately after the interview has taken place, in order to inform the listening and discussion in subsequent interviews.

At the same time, the status of interview accounts is itself disputed (Silverman 1993) as regards the relationship between the accounts and the world they describe. Since there can be no direct access to another person's experience, the best we can hope for is limited access through language and/or observation. However, neither is language a transparent medium reflecting an external and unchanging social reality; rather it is the main means by which we construct and interpret it. Researchers must then attempt to interpret

these interpretations in the light of the various contexts in which they were produced and in comparison with the other data produced during the study.

Inevitably, and rightly, some analysis of the material takes place during the interview itself, as the researcher and the individual talk together, pursuing some topics in greater depth and skimming others. Consequently the analysis develops further during the processes of transcription, as the researcher listens to the tapes and hears again, and anew, the words, tone, pace and inflection of the interview interactions.

However, the bulk of what is thought of as the formal analysis takes place from that point on and is focused on the text; –the interview frozen into words, lines, sections and pages, which thus form a limit to the researcher's interpretive thoughts. This transition is not a simple matter. The research interviews are about talk, –they are based on reciprocal hearing, speaking, listening, reacting, questioning, confirming– not reading. That transition, from talk to text, is not a neutral and unproblematic one. Yet, the original interview talk must be "cleaned up" in some way if it is to be made readable in order to record, analyse and report back on it. Therefore, some balance has to be struck between easy reading and full transcription. This decision has major implications for the types of analysis to which the interviews can then be submitted and consequently for the types of stories that can be contained in the report (Devault 1990). As Reissman has pointed out: "transcribing is an interpretive practice" (Reissman 1993). How much of the tapes are transcribed, and in what way, is itself part of the interpretation and analysis of the study. "Each representation is also a transformation" (Mishler 1986).

It is therefore important to adopt a style of transcription that fits with the study's theoretical/ paradigmatic perspectives and to recognise that interviews may contain different types of data, requiring different types of analysis, e.g. some portions may be suitable for a segmented coding scheme, others may need to be taken as whole units and thought about through the techniques of narrative analysis.

In addition, it may be that some, if not all, of an interview should be transcribed as poetry rather than prose. In our culture we tend to assume unquestioningly that people speak in prose. James Gee (Gee 1991) however, has drawn attention to the close links between naturally occurring talk and the tones and rhythms of poetry. Combining this with the markers and techniques of narrative analysis may mean that it is more appropriate, i.e. closer to the interviewee's sense and meaning, to transcribe people's stories into poetry. Reading, whether at the stage of interview transcripts or of research reports, is never a passive process: researchers and end readers will bring different responses to poetic representations. Richardson, in her work on different writing strategies (Richardson 1994), refers to the power of such

representations, citing Robert Frost's description of poetry as "the shortest emotional distance between two points –the speaker and the reader."

The actual processes of the analysis of qualitative data have long been a "black hole" at the heart of research reports; apparently not existing but swallowing up all the data that come near them and generating neither heat nor light until they reappear transformed into science in the final report. This uncertainty should be acknowledged. However, use of a variety of methods, within a unified theoretical approach to social research, can free the researcher to respond to all the interview data and to remain true to people's own topics and categories, expressed through their language, meanings and theories. Rather than viewing analysis as merely a mechanical or technical exercise, it should be considered as much an art as a science, and all the stronger for it. As Denzin says, "Interpretation is an art. It is not formulaic or mechanistic. It is learned only through doing" (Denzin & Lincoln 1994). In social life most experiences can be interpreted in a variety of ways. As a researcher inscribes her particular interpretation at any one time into words, they give it both a form and a limit; but it is fixed only as words. The possible meanings continue to be multiple and changing. The research journey to arrive at this interpretation should be clearly laid out so that readers of the research report can question both the process and the findings and imagine different ones.

> Analysis is not simply a matter of classifying, categorising, coding or collating data....analysis is about the representation or reconstruction of social phenomena. We do not simply "collect" data, we fashion them out of our transactions with other men and women. Likewise we do not merely report what we find; we create accounts of social life, and in so doing we construct versions of the social worlds and social actors that we observe (Coffey et al. 1996).

Once again, ideal research situations have to be balanced against the available time, resources and experience. However undertaken, transcription is very time consuming and involves many re-listenings to the interview tapes.

Since studies such as this one generate large quantities of unstructured, textual data, the use of computer software packages to aid in their analysis is becoming increasingly common, although there are also concerns about the implications of using them. These concerns centre around the possible clash between computer use and the aims of the research project; fears of introducing a culture overlaid with male and hard science connotations; fears that good intentions regarding a necessary diversity of approach and methods may be lost in a uniform approach to analysis through coding aided by

computer software; that such an approach decontextualises people's words thus losing their meaning (Coffey et al. 1996).

In opposition to these fears, others argue that such software packages are merely a tool, and a very efficient and effective one, to support, rather than determine a variety of approaches to qualitative analysis (Kelle 1995) (Fielding & Lee 1991). The handbook which accompanies the Nud.ist [Non-numerical Unstructured Data. Indexing, Searching and Theorising] package claims that its use enables the computer to be seen as "a tireless and endlessly efficient clerk, who never forgets." Therefore it can provide a speedy means of recording and retrieving data and the flexibility to play with it by making it easy to enter new ideas and to change coding schemes as new data, and thoughts, emerge. Supporters of the packages claim that it is only the mechanical aspects of analysis that are thus computerised, leaving the essential, interpretive work of generating and relating codes still firmly, but more effectively, in the hands of the researcher. Their use would therefore sit well with research projects such as this one, which aim to inductively generate themes from empirical data and the Nud.ist package includes some features which aim to minimise the dangers of decontextualisation. Therefore, despite my sympathy with the concerns voiced in the debate over their use, I decided to use the Nud.ist package [revision 3] in the analysis of this study's data in order to be in a position to come to my own decision as to its value or dangers.

However, as argued above, qualitative research is not a unitary enterprise, but rather needs to adopt a variety of approaches to fit the different situations in which it takes place. It therefore produces a variety of types of data, which need to be subjected to different styles of analysis. Reflecting on the interviews and listening to the tapes made it clear that they had generated both stories and question and answer sessions. Whilst the questions and answers fitted easily into the practice of segmented coding on the computer, the stories seemed to need to also be kept whole and subjected to the techniques of narrative analysis. By focusing on the different stories that people recount in the interviews it is possible to see how they have attempted to give an order and meaning to the events and experiences in their lives; how they have interpreted them. Stories are more than information storing devices; they construct and change both the events concerned and the people who tell or listen to them (Reissman 1993). They are meaning-making structures and thus provide another valuable access to other people's experience and a counterbalance to the dangers of losing contact with the contexts in which interview data are produced.

5.3.4 Presenting the findings

" Moving from field to text to reader is a complex and reflexive process (Denzin & Lincoln 1994). "

The decisions made about the end, textual representations of the research project also have major implications for the ways in which it can be read, received, responded to and understood. The writing up of qualitative research and Ph.D theses has, like all genres, its own codes and conventions. The traditional style is to include only brief excerpts from the original –prose– interview transcripts. This may be done with the avowed aim of producing a "multi-voiced" text and "allowing" participants' voices to be heard. In practice this is extremely difficult to achieve and the effect may be that people's voices are decontextualised and muted and thus unable to convey their own powerful messages and meanings. The quotations that the researcher has decided to select for inclusion are usually marked out from the main body of the text and printed in a different font. The continuing voice is that of the researcher, since these quotations are subsumed within the main text which contains her statements about the important substantive issues and themes and any theoretical perspectives. It is her generalisations and orderings that dominate the text and impose the framework for readers' expected understandings of the original participants' experience, with no acknowledgement of the context in which they were produced.

Research texts should strive to find more transparent ways to map the research journey, including decisions about how to represent the researcher's interpretations of the material. For researchers write stories, as well as listening to and analysing them. The way in which we choose to write is itself an analytical decision, not merely a technical or mechanical one; for "different texts inscribe different analyses" (Coffey et al. 1996). In order that readers are able to question our interpretations and imagine others, they need to be able to see where the words of the research report have come from; to be able to follow their journey from their original context in interview talk to their present context in the report.

In addition, we need to develop ways of inscribing research findings that are a better fit with the original aims of projects such as this one, which start from an urge to understand experiences and events from their participants' viewpoint. For the traditional texts direct readers to the authorial voice of the researcher, as she weaves selected extracts of other voices into her interpretation, leaving the reader with only "a translated text and a mediated life story" (Reissman 1993). These texts were designed to suit the aims of linear-structured and deductively accomplished scientific work, not

research such as this study, which has been purposefully constructed around a series of unstructured interviews and a dialogic design and inductively developed (Richardson 1994).

Fine highlights another way in which qualitative researchers' original aims may collide with their decisions about how to write:

> The risk for qualitative researchers has been, and continues to be, imperial translation (Fine 1994).

By this she means that researchers may start out with the intention of helping an exploited or subjugated group but end, by virtue of their writing style and format, by merely continuing to "Other" them by placing their story within the continuing tradition to which the social sciences are prone of colonial writing about interesting and exotic Others, who are different from Us.

The current menu of narratives for researchers to draw upon is also pitifully short and has led researchers to start experimenting with new ways of writing, or, indeed, with non-written forms of reporting, and to lay aside the belief that a definitive and final research report can be produced. Recent times have witnessed the gradual reconverging of scientific and literary forms of writing. As each has been deconstructed to reveal its framework of literary and rhetorical devices and markers, new mixed genres of writing have been able to spring up in these new spaces of uncertainty and blurred boundaries. Social science has been written up as fiction, drama (Ellis & Flaherty 1992), poetry (Richardson 1992), performance science and comedy. These different texts evoke different responses from their audiences, ones that may involve their bodies and emotions as well as their intellects.

> When we write social science, we use our authority and privilege to talk about the people we study. No matter how we stage the text, we –the authors– are doing the staging. As we speak about the people we study, we also speak for them. As we inscribe their lives, we bestow meaning and promulgate values (Richardson 1992).

The writing of a Ph.D. thesis has its own conventions and forms and these may not sit easily with the concerns expressed in this section. However, no research takes place in a vacuum and very little without being subject to external pressures and constraints. It is difficult to convey the process of this Ph.D. and the development of ideas on both method and substance that occurred over the years within a format better suited to linear and deductive research work; ways to develop more polyvocal texts are still being struggled

with. However the thesis itself is but part of the process of dissemination and of the learning of the researcher.

5.4 The research process

Having, through study of the available methods and the debates surrounding their use, arrived at some broad decisions about the research approach and methods best suited to this study in terms both of its subject matter and aims and of my own personal style and philosophy, the time arrived to try them out in practice. I had originally hoped to complete the fieldwork for this study in twelve months, from December 1995. However both practical constraints over arranging access and theoretical and practical difficulties in applying the methods combined to extend this. The interviews were not completed until March 1997 and reflection upon both their conduct and analysis prompted refinements and re-thinkings about the research approach, which greatly added to the time needed.

This process highlighted the difficulties in planning this type of research: the clash between acknowledging the need for reflexivity and flexibility on the part of the researcher and for working in empowering and participatory ways with those contributing to the research, and the need to set time and other resource constraints around a project. This leads to both moral problems [what is good for the research may not be good for the participants] and epistemological problems [through having to settle for less than perfect situations in any part of the research process]. In addition, the focus of the research may need to change as the data is analysed.

5.4.1 Access: obstacles, successes and compromises

As explained in section 3.2., having determined the aims and key questions for the project, and the approach most likely to fulfill them, it had been decided to seek access to a number of service users [likely to be about 20-25 in total] in the researcher's local area, who met the inclusion criteria for the study.

In practice, access to service users who were willing to take part in this study proved difficult; not because service users themselves were unwilling to participate, but because professional staff, at all levels, who considered themselves responsible for their well-being, were anxious. This anxiety was mainly framed in terms of concern lest people, whom they considered to be vulnerable, be upset or distressed by the research process. However, the obstacle at the highest level was provided by the Medical Director of the

Trust, who disputed the value of the proposed research approach, which, although very familiar to social scientists, is not yet widely accepted within medicine. This difference in understandings was also a problem, although less seriously so, when submitting the proposal to the Local Research Ethics Committee.

The ways in which these various obstacles were overcome provided an object lesson in both the power relations which structure the practice of social research and the pragmatic difficulties of applying theory to practice.

The relationship between the social sciences and medicine is not always an easy one. The social sciences themselves have a disputed knowledge base. Attempts to transfer research approaches underpinned by an idealist ontology and an interpretivist epistemology into a clinical setting are always difficult, but likely to be particularly so when the area of medicine concerned is that of mental illness, which is itself a disputed concept. In addition, practitioners, who grant access as a favour not a right, expect research to provide practical answers. Universities often have different understandings of and expectations from research in general and Ph.Ds in particular. Although my studentship was sponsored by the Regional Health Authority, which was helpful in gaining access to health service sites, making it clear that the Authority had sponsored a Ph.D, which would not necessarily be expected to provide answers and was not a piece of applied health service research, was often difficult.

The first approach with regard to access, was to the Chief Executive of the local Mental Health Trust, with whom I had some previous contact. He met with me personally to discuss the proposal, was happy to give it his support and asked for a brief written outline to take to his senior managers. It seemed paradoxical, in a study devoted to eliciting service users' views and perceptions, to be starting out in this way. It seemed that the people whose permission was the most important, to me at least, i.e. the service users themselves, were going to be the last ones to be asked for it, and only after a large number of other people had the opportunity to set limits around what could be undertaken. Nevertheless, as a junior researcher and with the contacts available to me, it appeared to be the only way to make the research happen at all and to offer the chance of accessing service users who are not in contact with user groups or day centres and so are not usually involved in such studies.

Armed with the Chief Executive's support, I submitted the proposal to the Local Research Ethics Committee [LREC] whose submission form alone poses an obstacle for qualitative researchers, since it has clearly been designed with a very different research approach in mind.

The remit of the LREC extends beyond those issues which might seem

to be obviously ethical, such as ensuring confidentiality, safety and informed consent, to the study's methodology, on the grounds that it would be unethical to allow research to proceed that could not achieve its aims. The Committee contained some members who were familiar with qualitative research approaches and had regularly approved similar work from the Community Health Council, of which I had been Chair. Being familiar with the Committee's ways of working, I was able to talk to the secretary and be invited to attend the meeting at which my application was considered. The Committee members wanted to know more about the procedures for access and sampling and were concerned about how sensitive matters were to be dealt with. Having allayed these concerns, I gained approval for the study from a prestigious quarter at the first attempt.

It was fortunate that I already had the support of my research committee at the university and of the LREC by the time that I ran into the concerns of the Medical Director. I had heard that he was not supportive and so spoke to him on the telephone, hoping to arrange a meeting with him. He was not encouraging:

> These people are a very vulnerable group and very open to suggestion. From your proposal I find it hard to see how your work could be either objective or valid –so what would be the point of letting it go forward? It would only waste people's time and might cause them distress. You need to give much more thought to your objectivity and the scientific validity of your findings. The findings that your research could produce might be interesting perhaps, but they can't have any real value. It has no definite questions to answer. Real research should have hypotheses that can be tested, whose findings are valid and can add to the knowledge base and move it forward. I'm very surprised that your supervisor has passed it. It needs much clearer criteria, proper protocols and a much more structured approach.

He declined to meet with me to discuss the proposal. "It's not my job to teach you about proper methodology; surely your supervisor should have done that." He suggested I wait to hear from the LREC, clearly expecting that my proposal would be rejected.

> The Ethics Committee do a very thorough job in screening out cavalier research. I may not always agree with them when they send back my protocols mucked about, but actually they are helpful because they are at least all professionals working in the field, not a collection of doctors in an ivory tower.

When he learned that the proposal had the support of the Ethics Committee as well as the University and his Chief Executive, continuing to oppose it became difficult. It was agreed that I would submit regular reports on the progress of the research to the Trust and the path was thus cleared for the next layer of negotiations.

Access to those who participated in the first interviews, the User Group at the Day Centre, was secured through the support of the Community Mental Health Advocacy Worker, who was currently facilitating that group's meetings. This Group was selected because its members were all people with severe and enduring mental health problems, who had received most of their treatment and support in community settings. I first spent an afternoon with the worker, discussing the study's approach and aims. She was very encouraging and supportive, providing me with many contact names throughout the county and arranging for me to attend the next meeting of the group, providing this was agreed by her Steering Group, which did not meet for another month. Her advice on working with mental health service users was: "It's really very simple: it's just a case of treating people as people, as you yourself would wish to be treated."

The Steering Group did have concerns, again about causing distress to the people who participated by dredging up past and painful experiences and saw their role as being to protect vulnerable people from this. They therefore asked me to attend their next meeting to discuss these issues. Another month's delay. Then their approval was given.

Following on from this, I was able to arrange to spend a day at the Day Centre, to meet the manager and other staff and talk with them about the study in the morning, then to attend the User Group meeting in the afternoon. The Advocacy Worker introduced me to the group and I talked with them about the study, explaining how it might be conducted and what it hoped to achieve. The group [Linda, Eric, Barry, Gary, Tim, Mary and John; all participants' names have been changed] were enthusiastic about the idea of participating, as a group rather than individually, and immediately suggested a number of areas that they would like to talk about in the interviews and a date was arranged for the first one: six months after my initial meeting with the Chief Executive, and so already well into the year I had allowed for my fieldwork.

At the same time I was making contact with a range of middle and senior managers, professional staff and clinicians at the Trust and meeting with them to talk about the study. Many were very impressed, enthusiastic and supportive, which encouraged me to carry on, and a number of obvious favourable sites and contacts became apparent from these discussions. However, I was rapidly realising for myself that what the text books said about

access being difficult, time consuming and never clear-cut was absolutely right. With each new person you have to start all over again, no matter how many times you have said it all before, and you have to remember that it is new to them and nothing can be taken for granted. In addition, in a large and physically scattered organisation, such as this NHS Trust, it is rarely clear whose permission needs to be sought and/ or who needs to be informed that the research is being undertaken.

The next formal obstacle was to give a presentation to the Trust's Mental Health Managers Network and answer their questions. By this time it had been agreed this would be for their information only, not approval or otherwise. It was felt to be necessary it order to ensure a clear path throughout the Trust for the research. The full proposal was circulated before the talk, along with two articles from the British Medical Journal on qualitative research. There were a few questions about sampling and aims, but the meeting was generally supportive and useful contacts were made. One senior manager said, "At last, a piece of real research, properly drawn up, thought through and supervised. I thought as I read through it "My god, this poor girl has put her blood into drawing this up. It's really good. Just what we need."

The next formal meeting was with the Mental Health Team for the north of the county. I had decided to approach them in order to try to secure access to more people with severe mental illness and in receipt of community treatment and support, but resident in a different part of the county. Having read my proposal, they were very helpful and supportive and immediately suggested six possible people. I left copies of the introductory letter and contact form [see Appendices], which were handed out by the relevant Community Psychiatric Nurses and quickly received replies from four of those people, saying that they would like to participate. I then contacted them and made arrangements for the interviews to take place in a venue of their choosing [their own homes]. [Carole, Joseph, Harry and Irene]

By the time that eight interviews had taken place [May 1996], a number of themes were already starting to emerge from the data and it was time to start negotiating access to other sites. The interviews thus far had all been undertaken with people who had experienced most of their care and support in community settings. I now wanted to compare their accounts with those from people with the same diagnoses and symptoms, but who had received most of their care in institutional settings. Initially the approach to this group of people was again through an Advocacy Worker and after a meeting to seek the agreement of his Steering Group. The Group's concerns were about genuinely informed consent and enabling people to feel free to cease their participation at any point, how the data would be analysed and written up, and why anyone would want to take part. After this their support was

given and two new sites agreed: a sheltered employment scheme for former long-stay patients who have been resettled, and the Rehabilitation Ward on the hospital site.

At this point I was approached by two people in my local area [Mark and Jane], who had heard informally about my study and were interested in participating. I arranged to meet with them to talk about the project and they agreed to begin interviews. Their contributions gave me access to the experience of living with severe mental illness in the west of the county and in different social situations.

After this I met with the manager of the hospital ward, who was very supportive of the proposal, feeling that it was a good fit with the ethos and aims of the ward. By this time I had a formidable array of support behind me and so it was much less likely that any individual would feel able to oppose the study. In addition, approaches were being made to only those sites and people which were felt to be supportive of this kind of approach and I had prepared a very full background pack to circulate in advance, which addressed the main issues that had arisen previously. The manager felt that participating in the research would be both therapeutic and empowering and identified four individuals who could be approached, once the ward's consultant had given her approval. It took more than two months to arrange a meeting with her.

In the meantime 20 interviews had been completed and I arranged to meet with the manager of the sheltered employment scheme. He was willing to participate, provided his Senior Clinical Nurse agreed. The meeting with her revealed how much research they are being asked to contribute to and the problems this causes. They were worried that they were being over-researched, that there was no research strategy and so studies seemed to duplicate one another, and that they rarely received any feedback, which made them wonder why they were doing it, apart from providing work and qualifications for other people.

After this meeting, six people were approached by the nurse, with my letter and contact sheet, and agreed to take part. [Mabel, Mike, Lenny, Paul, George and Matthew.] All of them except Matthew had spent a long period of time [several decades] as hospital in-patients on long stay wards.

By this time the sample consisted of 19 people with a range of diagnoses and of experiences. Finally I returned to the hospital site. The consultant with responsibility for the rehab. ward had been happy to give her approval to the study. The Ward Manager therefore took me to meet four people that the staff had identified as possible participants. After this initial meeting two of them, Ian and Darren, contacted me to arrange to start the interviews.

5.4.2 The sample

In this way, and in accordance with the principles discussed in section 3.2. for sampling for this type of research, 21 people took part in the 47 interviews which generated the data for this study. Fifteen were men, 6 women. They were aged from 18 to 65. They lived throughout the same county, some in very rural areas, some in urban. They all had a diagnosis of either schizophrenia or manic depression and had been in contact with the local mental health services for more than 3 years. Some had received most of their treatment and support in the local psychiatric hospital, some in community settings. They were all White [reflecting the county's population] and from a range of social classes and situations. The geographical area was covered by one Health Authority and one Social Services Department and one Mental Health NHS Trust.

The participants were:

Barry, Mary, Eric, Gary, John, Linda and Tim, who attended the same Day Centre, for people with severe and enduring mental health problems. They each attended for up to three days per week and were the main members of its User Group. None of them had any paid employment. Mary was married and lived in a local council house. In her fifties, she died suddenly during the time of this study. Linda, in her early twenties, had a two year daughter and lived with her in a council flat. None of the men were currently in a long-term relationship and all lived alone. Eric was aged 42 and had a diagnosis of manic depression. John was 57 and had a diagnosis of schizophrenia. Tim was 48 and had a diagnosis of manic depression. Barry was 32 and had a diagnosis of schizophrenia. Gary was 26 and had a diagnosis of schizophrenia. They took part in seven interviews, as a group, although not everyone was present for all of them. Barry also, at his request, undertook one individual interview because he did not always feel able to express his views in the group. All the interviews took place in a small and private room at the Day Centre, approximately once a month between April and October 1996. The group was user-run and the members were confident that the room was sound-proof and that no staff would enter without first knocking and asking permission to come in.

Carole, Jane, and Irene were married and/ or had young children. They spent much of their days looking after the house and children. Carole was in her forties and had a diagnosis of schizophrenia. She lived with her husband and one son in a council house and attended an NHS run mental health drop-in centre one day per week. Jane was in her thirties and had a diagnosis of manic depression. After two in-patient episodes, she had decided to try to cope alone as far as possible, without medication or help from the mental

health services. Her husband left her and filed for divorce and custody of their three young children during the time of this study. She continued to live in their jointly-owned house and was successful in winning back custody of the children. Irene was in her sixties and had a diagnosis of schizophrenia. As her children are grown up and living away from home, she lived with her husband in their own, large house.

Joseph was in his late twenties and now living alone, but with the active support of a neighbour, in the community. He had been in and out of hospital over a number of years and had spent several years living and working within a monastery.

Mark and Harry had retired from part-time jobs, one as a lecturer, the other as a labourer. Harry was in his sixties and had a diagnosis of schizophrenia. His wife had died many years ago. He now lived alone and attended an NHS run mental health drop-in centre one day per week. Mark was in his late fifties and had a diagnosis of manic depression. He was married and lived with his wife in their own large house.

Carole, Jane, Irene, Joseph, Mark and Harry were all interviewed, by their choice, in their own homes, sometimes, again at their wish, in the presence of their partners/ carers.

Lenny, Matthew, George, Mike, Paul and Mabel attended an NHS run sheltered employment, packaging workshop, for between three and five days per week. Apart from Matthew, they had been long-stay patients at the hospital but were now resettled in the community. Mabel had been married but her husband divorced her whilst she was in hospital. After decades of living in the hospital she was resettled to a group home and now lives alone in a council flat. She was 62 and had a diagnosis of schizophrenia. Matthew was 32 and had a diagnosis of schizophrenia. He lived with his sister and her family, in a council house. Lenny, George and Mike had all lived in the hospital for decades. As a result of the resettlement programme, they now live in privately run group homes, where they each have their own room and all their meals are provided. Paul was in his late thirties and had a diagnosis of schizophrenia. He lived alone in a council flat. Mabel, Paul, Lenny, George, Mike and Matthew were all interviewed individually in a staff office on the upper floor of the workshop. This posed some problems as it was not sound-proof and staff occasionally came in to retrieve books or files without any warning. It was also unfamiliar territory to both the service users and the researcher.

Darren and Ian were both young men in their early twenties. They had been diagnosed as suffering from schizophrenia and had been living mainly on the hospital site for a number of years. A range of activities and classes were still available to them there, for example use of the gym, art classes, com-

puter classes. Both did make use of them intermittently. Ian lives with his girlfriend, Laura, who has a teenage daughter from a previous relationship, who lives with Laura's parents. At the time of the interviews the hospital ward on which they were patients was in the process of being refurbished and all the patients had been temporarily re-housed in a variety of individual and group houses on the site. For many of the patients this was a welcome change and one that granted them greater autonomy and privacy. For the staff, however, it was a difficult time. Ian and Laura were sharing a small terraced house, previously a staff house. Darren was sharing a small house with two other young men.

5.4.3 Generating and recording the data

In accordance with the principles discussed in section 3.1., the data for this study were generated through a series of unstructured interviews. 47 were carried out; seven with an established service user group, with seven members, at a day centre run by the local mental health NHS Trust, 18 with six individuals in their own homes, 16 with six people at a sheltered employment scheme run by the local mental health NHS Trust and six with two individuals living in the hospital.

Although the people who took part in the study were accessed through a variety of routes, everyone was given written and spoken information about the project and asked to sign a consent form [see Appendices] before any interviews commenced. The introductory preamble stressed the independence of the researcher from any service providers, outlined the purpose and structure of the research and the ways in which the interviews could be carried out and recorded. Everyone was assured that the information they offered in the interviews would be confidential, stored securely and anonymously and destroyed after the research was completed; and that they would not be identified in any report. In particular, it was stressed that people were free to stop the interviews at any point, or to move on to other topics, and that participating in this study would have no direct effect, for good or ill, on their care and treatment.

The interviews were tape recorded whenever possible. When this was not possible, either for practical reasons or because people did not wish to be taped, notes were hand written, then more fully written up and entered into Nud.ist within twenty-four hours of the interview.

The interviews took place between April 1996 and February 1997. Each one lasted for between 45 minutes and two hours. The full interview timetable is contained in the Appendices.

Although it is, and should be, difficult to describe a typical interview,

since they were deliberately designed to be flexible and sensitive enough to respond to individual situations and needs, they were all underpinned by the same general values and aims. These were that:

- the scope and duration of each interview should be determined by the concerns of those participating;
- such questions as the researcher asked should usually be open-ended and non-directive;
- that careful, attentive and analytical listening is as important as asking questions;
- that participants' views, feelings, meanings and values should be heard and clarified;
- that there is space and support for people to tell their own stories, in their own terms;
- that each interview should provide feedback from, and build upon previous ones in ways that allowed participants to amend, correct, add on to or delete earlier accounts.

5.4.4 Analysing the data

After each interview the tapes, or notes, were transcribed, in their entirety, by the researcher into prose and entered onto the Nud.ist programme. This in itself entailed many hours of careful listening to, and thinking about, the contents of the tapes/ notes. This both guided the original codings and led on to new ideas for future interviews/ codings. It also provided opportunities to reflect upon the conduct of the interview and the interaction between the researcher and the participant. During the transcription the names of the participants, and any other clearly identifying details were changed, in order to preserve people's anonymity.

Each interview transcript could then be individually coded. At first the codings were very broad and under two main headings [known in the programme as nodes and identified numerically according to their place within the pictorial coding "tree"]. Node 1. was for people: each transcript would be coded for storage under the name of the person, or group, participating; the location of the interviews; the diagnosis; gender; and age.

Under node 2. the content of each interview was coded for storage under four main headings, or sub-nodes:

- 2.1. mental illness;
- 2.2. daily life;
- 2.3. self and others;
- 2.4. free themes, such as user involvement, choice and information, and discussions about social research, which did not fit easily into the other three headings.

These were chosen, after reading through the early transcripts and listening to the corresponding tapes several times, as broad categories which would cover everything which people discussed in the interviews.

As the number of completed interviews increased, these four main substantive nodes in turn were refined to develop a number of sub-nodes, giving a total of 50 nodes after a few months. For example, the main node on mental illness, identified as 2.1. developed 7 sub-nodes:

- 2.1.1. the course of the illness;
- 2.1.2. the type of illness;
- 2.1.3. treatments;
- 2.1.4. staff;
- 2.1.5. what helps;
- 2.1.6. community care;
- 2.1.7. changes.

Since some of the interviews had been conducted in the presence of, and contained data from partners and carers, another main node, Node 3., was added at this stage to store their contributions.

Several months later, after many re-readings and re-listenings, in order to remain familiar with the whole data set, as well as under the influence of ideas from other sources such as readings and discussions with other researchers or practitioners, I decided to add a new fourth main node, as well as further developing the substantive sub-nodes. This new node, 4., was headed emotions and values, with two sub-nodes; 4.1. negative and 4.2. positive. Each of these also developed sub-nodes.

By the time the coding scheme was completed i.e. no new nodes seemed to be needed, there were 138 nodes [for full scheme see Appendices] and the coding scheme had developed to become not just a storage device but also

the basis for a conceptual structure to both analyse individual node trees and to make and explore links between them using the package's various search mechanisms.

In parallel with the coding of the transcripts, I was also studying each one using techniques from narrative analysis, such as picking out the main "storyline[s]" from both individual interviews and the whole series with each person; using narrative markers to extract stories from the text, for example about the time of diagnosis, with the aim of comparing these whole stories across the sample; and examining the common metaphors, adjectives and similes that people used to describe their experience, which highlighted areas they found difficult to talk about and the cultural menus that they were drawing upon in efforts to "place" and make sense of their experience. I made notes to summarize the content of each interview and series of interviews and to list the main underlying themes and images and transcribed some of the crisis stories into poetry. [see Appendices for Ian's account of his first illness.] In this way I became very familiar with each interview and the contexts, both of place and of each individual life, in which it took place.

Since the analysis of qualitative data is also an area that is difficult to describe, it is often compared to translation, with the researcher trying to translate between social worlds. Just as, linguistically, good translation comes from more than the mere one-to-one correspondence of words, so too with interview texts. The translator's job is always to try to convey also the cultural sense and resonances of the words and expressions used. She/ he therefore needs a thorough grounding in the meanings and understandings of both worlds. This entails both breadth of cultural knowledge and depth of detail.

As the process of analysis proceeded, themes, patterns, questions and comparisons would begin to emerge both within particular nodes or stories and across different ones. For example, by bringing together and studying all the coded segments and the stories where people were describing their disappointment with their current daily life, and their fears that they would never again be in open employment, these began to build into a coherent argument about the kinds of dilemmas and judgments they were having to face. These then linked into the difficulties they were describing in other areas of their lives, such as their relationships with professional staff [for example, they could not be honest with staff about their state of health because they feared they might lose benefits by doing so.] Gradually an overall theme for the study began to develop by looking at the dilemmas and ambiguities, the conflicting pressures, which people were describing in all areas of their lives; a feeling that, regardless of the location in which they had received their treatment and care and of the policy change to community care, they had

no clear place in society; that they were "lost in space".

5.4.5 Presenting the findings

Research findings are presented to a variety of audiences and through a variety of media.

During the fieldwork for this study, I had frequent contact with both participants, their families and friends, and staff because I was returning to particular locations to conduct a series of interviews with people. Each time I would be asked how the study was progressing in general and how their interviews were fitting into it in particular. Much informal feedback of the study and discussion of different types of research took place in this way.

During this period I was also providing regular written updates on the study to the Chief Executive and Medical Director of the Trust. These sometimes led to requests from senior staff to meet with them to discuss particular findings, for example people's views on the possible closure of the hospital site or their experiences of CPA.

The User Group at the Day Centre decided to use some of their interview transcripts as material for joint discussions with staff at the Centre on their experiences of care management and medication. The sheltered employment scheme published a monthly newsletter, to which I contributed articles at the beginning and end of my time there.

However, it was difficult to provide much more than this, partly because of the length of time that elapsed between the fieldwork and the writing of this thesis, and partly because its aims and concerns were different from the more immediate, practical and local concerns of the participants and staff. As stated before, it was fieldwork for a Ph.D., not a piece of applied health service research. Nevertheless, I was not unhappy about this part of the feedback, since I felt I had fulfilled the promises I had given to both staff and participants and had been happy to comply with any other requests that arose. In particular I was as confident as I felt I could be that no-one who participated in the interviews had been left feeling unhappy or "used" by the process.

The later stages of the research process and the presentation of findings were much more problematic. The study aimed to examine the experience of severe mental illness from the perspective of those who participated in the study and based upon their meanings and understandings of it. However, when it came to presenting its findings a number of dilemmas were apparent. I had aimed to provide comfortable interview settings, which would encourage participants to talk fully and freely and where we could co-jointly establish meanings, and yet I did not share with them the next stage of es-

tablishing and presenting in a textual form my understandings of all their understandings. In part this again stemmed from our different aims for, and needs from the study and so might be easier to deliver in other types of research project. I struggled with many pressures and concerns; to both work in a participatory way and meet the time limits and academic demands of a Ph.D.; to support people in telling their stories, because that is where many of the most significant issues are revealed, and yet to protect individuals from identification in written reports; to remain true to their understandings and concerns and allow their voice to be presented in academic settings and yet to retain my interpretive authority. I often wondered whether it was helping their cause to write in these ways or rather exposing them to further surveillance. Indeed, what does it feel like to have your life written about and who does it benefit?

I found no comfortable solution to these problems. The themes which I picked out and developed from the interview transcripts and the Nud.ist coding tree were ultimately mine. The decision to write about them in the separate chapters and in the style that follows contains dangers of fragmenting the sense of whole people and lives, the context that gives meaning to meanings, but has the advantage of greater protection of individual identities. If I had world enough and time, no doubt I would do it differently.

5.5 Conclusions

Undertaking the fieldwork for a social science Ph.D. has long been described as, and remains, a lonely and introverted process. The aim of the project may be, as here, to undertake empowering research, but this is difficult when you are yourself in a relatively powerless position and working alone. Although researchers may start out, as I did, by thinking of their role as a link between two worlds and belonging to both, the reality may be that, during long fieldwork periods, you feel a part of neither and are, like the participants, lost between two worlds. As the novelist Patricia Duncker writes, "No-one ever pointed out that research would be a dull, confusing, depressing, endless chore and that writing a thesis is a lonely, obsessive activity. You live inside your head, nowhere else. University libraries are like madhouses, full of people pursuing wraithes, hunches and obsessions." [Hallucinating Foucault. 1997] Throughout the process there are problems and obstacles, both practical and philosophical: the sense of uncertainty and compromise is continuous.

However, the process has to stop at some point and such lessons as have been gained from it can be built upon in the next piece of work. The research methods lessons learned from undertaking this study are both general

[concerned with the lack of strategic development and resource commitment to research work and career structures for researchers and the continuing difficulties in developing and applying research methods more adequate for this type of work] and specific to particular parts of the process.

Gaining access to service users to participate in the study was extremely complex, time-consuming and potentially, since it was achieved via various layers of professional staff, in conflict with the aims of the project. Sensitive negotiations had to take place with gatekeepers throughout and the project was reliant on their explanations and understandings of it in their initial discussions with potential participants. If the service users had been approached through other channels, for example through voluntary organisations, the process may have been quicker and less complex but would have resulted in a more limited sample. The eventual advantage of the approach adopted here was that it gave access to people not all of whom were in contact with groups and organisations.

The Local Research Ethics Committee is another, powerful gatekeeper in social research. Now that qualitative research is becoming more common in Health Service settings it may be that its composition will need to be adjusted to reflect this, with more of its members being familiar with the paradigms and problems of this type of research approach, and its submission form redesigned to better fit qualitative proposals.

Given the practicality of power and politics in the area, it was generally possible to access service users only through sympathetic staff and at sites already known to be themselves striving to pursue values similar to those underlying this project. It was apparent that this was often difficult for staff, since organisational structures and policy guidance did not always support this style of working and were sometimes in direct conflict with it. It seemed to be the case that service users were most respected and empowered where the staff supporting them were too, and had working practices that enabled this. The local Mental Health Trust was committed to increasing service user involvement and empowerment and to striving to provide more user-centred services. It may be that other Trusts would not have been willing to allow this research to take place and the recommendations contained in this study are not intended to be seen as criticisms of this particular Trust. On the contrary, it is nationally recognised for its good practice and openness, yet, even here, there are problems for those in receipt of its services.

Whilst it was valuable for the research to be, and be seen to be, undertaken by an independent researcher, this did make it more difficult initially to find out whose approval was needed, who needed to be told about the study and by whom, and who had the authority to grant further access. On the other hand, staff within the Trust were equally bemused by the amount

of research to which it is now being asked to contribute and confused about the purpose and aims of it. Their concerns about the lack of any clear, overall research strategy that could be explained to them, and of any feedback from the work undertaken seemed justified and to highlight areas that need attention, given the continuing encouragement to academic researchers to develop links with Health and Social Service staff and to undertake work in partnership with them.

Gaining access became easier as the process went on. This was in part because I could, at each stage, start by laying out the levels of approval that I had already gained, and in part because common themes and concerns were emerging that I wrote up and addressed, together with detailed information about the background to the project and its research approach, to form a "Research Pack" that I could hand out before the meetings.

When I did finally come to meet with the service users themselves, they had their own understandings of the nature and purposes of research and their own concerns about it, which also had to be negotiated with before the interviews could commence. These covered such a wide range that they are difficult to summarize here, but some examples were:

- at each interview with Ian I encouraged him to talk about his experiences and the things that were important to him, but he saw this as "just rambling; no use to you. You ask me some questions and I'll tell you the answers."

- at the interviews with Irene and her partner Dennis, they explained that their aim in offering to take part in the research was to gain another way of making clear their view that the old psychiatric hospital should be kept open and was itself a vital part of community care for people with severe mental illness.

Nor did I assume that the signing of the Consent Form meant that people were willing to continue with the series of interviews. Their consent was renegotiated throughout and their questions and queries about the progress of the research fully discussed. In some research paradigms this would be seen as contaminating the data; in this one it seemed an integral part of conducting it successfully, since it is only through open discussions that people will feel free to develop with the researcher the kind of intimate data that a study such as this one requires.

The very different views of staff and of service users about their involvement in the research, can be seen through the following quotations:

> You have to be very careful talking to users because they're so vulnerable and will get upset. They have no insight into their condition, have unrealistic expectations and are often highly drugged. [Senior Clinical Nurse]
>
> We want to be heard. Staff don't listen to us or talk to us or take us seriously. We want to share our experiences with others and be involved in the decisions about us. We need much better information etc. and we've enjoyed taking part. [User Group]

Both have to be successfully addressed in order for the research to take place at all.

The approach taken to generating the data, via a series of unstructured interviews, was successful in providing the type of data needed and in being acceptable to those participating. People found the interviews enjoyable, even when they covered difficult and upsetting topics, perhaps because they felt in control of the interview, encouraged to speak in their own terms and time and listened to and respected as experts on the topic. Once I had gained the confidence to sit back and allow the interviews to follow their own momentum, they did provide opportunities for people to tell and develop their own stories about, and understandings of themselves and their experiences.

However, this approach is again time consuming. Even a short interview [45 minutes] can take three or four hours to transcribe in full, an hour to code on Nud.ist and another hour to annotate for stories and narrative markers.

The original idea of feeding back the transcript from each interview at the next one, as a basis for discussion and to correct and amend it, proved problematic in practice. The first interviews were with the Day Centre User Group. At first they were very keen to see the transcript each time and read through it. They even decided to show some to staff at the Centre and discuss the issues in it with them. However, as our relationship developed and the interviews lasted longer they lost interest in the transcripts, found them too long to read through and told me not to bother any more. A different problem arose with the individual interviews, which posed an ethical dilemma. Whilst most people were willing to agree to be taped at the first interview, some were concerned by receiving the transcript at the start of the next one. They were willing to contribute to interviews rather than questionnaires just because talk seems so ephemeral; to leave no record of itself. Whilst the idea behind returning with the transcript was to encourage participants to have more input into the developing discussion and analysis, its effect was the opposite, making people much less willing to speak at all. Therefore, with misgivings, I stopped doing it and instead checked and discussed issues from the previous interview only verbally, unless people asked to see the transcript.

The tapes did provide a valuable way to go back over interviews, to rethink the conduct of individual ones, to consider ways to improve one's own research practice and, more generally, to reflect on the interactions that take place in research interviews.

Being an independent researcher, with no background in either nursing or social work or any links to service providers, was valued by participants. They felt able to talk more freely to me, recognised that I had no "staff attitudes" and realised that they genuinely were more knowledgeable than me in many areas. Being what the textbooks describe as "an incompetent outsider" (Hobbs & May 1993) and not in control of the interview can be an uncomfortable feeling but is necessary to generate the required data and valuable for the freshness of vision that it provides and that can never be recaptured once anyone starts to become knowledgeable about a particular area.

The interviews were influenced by many pragmatic considerations such as their location, the kind of introductory talk about them that people had been given by the staff who first approached them, the status of the people taking part and the ways in which they viewed me. I, in turn, was occasionally concerned about safety issues and would institute some more formal procedures in order that someone would know where I was interviewing and what time I should be returning. Even professional researchers are often poorly served and supported in these areas.

The interviews produced a mass of textual data and I found little clear guidance on how to transform it into a research report. Studying for a Ph.D. provides a valuable opportunity to experiment with new approaches or combinations of approaches in response to developing thinking about the research process and to the substantive themes that are emerging from it. The decision to try out a computer software package provided a structured way to start to tackle the problem and was valuable for that alone, provided one remained mindful of its pitfalls also. The decision about which package to use was largely pragmatic, since Nud.ist was the only one readily available. If undertaking a similar study in the future I would try Atlas/ti, which may offer more visual, creative and interlinked "loose" structures (Barry 1998). Once again, researchers and projects need time to develop new skills and patterns of thought in order to be able to build on from previous research. Using Nud.ist was also valuable in providing a flexible and efficient way to store, structure and manage the data. Although time-consuming to code, it provided an easy way to store the same piece of data in several different coding nodes, to keep track of the development of each node and to develop links between them. The time spent inputting was repaid by the ease of searching, retrieving, moving and linking data segments. The danger of using

it was that the sense of the people, lives and contexts that provided the data would be lost. This is less of a danger in a small project like this one with only 21 participants and one researcher and was further counterbalanced by the whole narratives and by the narrative notes on each interview.

Given that there can be no direct access to other people's experiences, researchers have to struggle to develop better and more accurate ways to access, interpret and represent other people's interpretations of their experiences. This is no easy matter and the research process is, inevitably, continually selective, incomplete and partial. The original experience is selectively retold to the researcher, who selectively records it, selectively transcribes that recording, selectively analyses the transcription and selectively writes up the analysis, which is differently read and constructed by different readers. Therefore all research decisions are not merely technical but also have serious implications for the final text and understandings of the project; they are all part of the interpretive practice.

In particular, putting the sense of selves and contexts and whole people back into a written, academic report is difficult. To produce a text that remains true to the concerns and views of the participants in all their complexity as well as possessing academic respectability is a continuing conundrum at both a micro and macro level. For example, should people's actual words, expressions and hesitations be reproduced as a valuable guide to their meanings, or should they be interpreted, condensed and edited into "academic-speak" in order to secure for them greater respect and a hearing in those circles, or is such a transformation itself a distortion and betrayal in an area such as this where people are still struggling to find their own language to represent their experiences?

Because research projects are still largely judged by and through their written reports, this unresolved difficulty is a crucial problem. This project may, through the ways in which it was designed and carried out, have produced some beneficial changes in local practice and in the ways in which its participants think of themselves and express their experience. However, it is still struggling to find satisfactory, written ways to present its conclusions and to write a research story which is less mine and more the participants'. If the experiences of those who participated in this study are not to continue to be "lost in space" in research too, then more adequate methods must be sought and adopted.

6. BRIEF ENCOUNTERS; SERVICE USERS AND STAFF

6.1 Relocating the research problem

Chapters Six, Seven, Eight and Nine of this thesis consider and discuss the main concerns that emerged from the interviews with service users. Carrying out the series of interviews with each person and reflecting upon what was discussed in them led me to relocate the research problem in order to attempt to produce a thesis which more accurately reflected their experience and concerns. Consequently these chapters include reference to bodies of literature beyond those in Chapters Two, Three and Four. Those early chapters reviewed the issues and areas most written about for severe mental illness but the interviews highlighted many other areas where sociology could contribute. The relevant literature from these areas is included here and linked to the findings in each chapter.

6.2 Introduction

This chapter examines the participants' experiences of, and views about, interactions with a wide range of mental health professionals.

The material in this chapter is based upon extracts from the interviews with service users. All the extracts coded under node 2.1.4., which covered all references to staff, were printed out for closer study and all the transcripts were also string-searched for the following words, with the findings of each search then stored as a separate sub-node:

- 2.1.4.1. social worker;
- 2.1.4.2. care manager;
- 2.1.4.3. community psychiatric nurse [CPN];
- 2.1.4.4. key worker;

- 2.1.4.5. G.P.;
- 2.1.4.6. doctor;
- 2.1.4.7. psychiatrist;
- 2.1.4.8. nurse;
- 2.1.4.9. staff.

Node 2.1.4. was chosen for further study because I was aware that it covered a topic which arose in all the interviews and on which people held strong views.

Having re-read all the material in the main node and the sub-nodes, it became apparent that there was a large gap between what people wanted and hoped for from members of staff and what they generally received. Consequently this chapter begins, in section 3, by drawing together the material which describes the ideal member of staff. Section 4 contrasts that with common experiences of encounters and relationships with actual staff. Section 5 concludes the chapter by discussing this gap between ideal and reality and highlighting the consequent dilemmas that service users therefore face in their dealings with staff and some of the consequences that may follow from this.

Direct extracts from the interview transcripts are quoted in italics.

6.3 Ideal staff

A clear vision of the ideal member of staff, from whatever profession, emerged from the discussions with service users. The particular qualities that they value in staff are:

- a cheerful and lively personality;
- a genuinely caring attitude;
- the ability to listen;
- having time for everyone;
- being well known, reliable and easy to contact;
- being knowledgeable and a good communicator.

All those interviewed described the pleasure they gained from interactions with staff members who are pleasant, cheerful, sensitive, bright, lively and funny. These were people who seemed pleased to see them and brought some sense of joy into their lives.

CAROLE: *I want someone who's pleasant and cheerful; someone who CARES for you.*

Carole, interview 1.

DARREN: *I like the ones who are bright and lively.*

Darren, interview 1.

IAN: *She [Key Worker] pulls funny faces through the window at us, and all this carry on. [Giggles]. And she goes, "blub, blub, blub," like that, with her mouth. [Running two fingers over his lips.] She's really funny. She's crazy. [Giggles.] She makes us all laugh. She's crackers. She's the best one I've ever had. She's a lovely lass.*

Ian, interview 2.

The service users placed high value on staff who could make them feel good about themselves. They wanted to feel that members of staff respected them and were interested in them as people, not a collection of symptoms; treated them as adults, not as children; were polite; empathised with them; gave all their attention to them when they were present and were reliable and dependable. The importance of this could be deduced not only from what people said but also, and perhaps more powerfully, from the way in which their expressions lit up and warmth infused their words as they were describing their feelings about staff whom they considered to be good.

BARRY: *She really tried to help us a lot. She was better than the other staff because she really used to care. Talk to you and that. A bit like you, she would just talk and listen to you. Take you to one side, and really listen to you and try to help you.*

Barry, interview 1.

ME: *What is it about the hospital that makes it feel safe for you both?*

IRENE: *The staff....*

DENNIS: *It's the staff....*

IRENE: *Yes, I think it's the staff. You go in and see these familiar faces, and you know you haven't got to do any explaining....um, ...you can just relax and ...er,....they don't find you peculiar, and they know you're not mad....And they put their arms around you and...er,...that's it. That's it!*

DENNIS: *And Irene's demons, or whatever they are, don't follow her there, do they?*

IRENE: *No.*

Irene and Dennis, interview 1.

IRENE: *The CPNs who come to see me each week are lovely people. They're giving people. They GIVE of themselves.*

Irene and Dennis, interview 2.

ME: *What do you think makes somebody a good doctor?*

MATTHEW: *...ooh,...It's just the way they treat you like, you know? Well, I haven't got any complaints about my doctor like. Mind, I've had my doctor a long time now. But he treats you alright, you know? He treats you nice.*

Matthew, interview 3.

MABEL: *She's [Key Worker]...I really, really think the world of her. And if anything happened to her...I don't know what I would do...cos she's really....I can depend on her. Do you know what I mean?*

Mabel, interview 1.

It was not possible to find an excerpt from any of the interviews that described the positive effects of feeling that staff were really listening to you and accepting your meanings and concerns. There were, however, many that described the frustration and powerlessness engendered by the common experience that, no matter what you said or how you said it, nobody really heard you and paid attention to your concerns.

JOSEPH: *The Social Worker's no good. You can see, she's dead in her eyes. It goes in one ear and out the other. She never really takes it on. She's brain dead.*

Joseph, interview 1.

GARY: *Also, as well, when you're talking to people -like professionals- you feel as though you're not being listened to as well, you know?*

Gary, group interview 2.

MARY: *I'm sick of bloody telling you that there's nobody listening. That's what I'm trying to say to you. I'm still shouting it out, "Will somebody stop and LISTEN?" I'm asking for help, and no bugger's listening.*

Mary, group interview 7.

Service users were well aware of the pressures upon staff and of their heavy case loads. Consequently they greatly appreciated staff who had the quality of stillness, of giving out a feeling that, however much else they might have to do, when they were with you, you were the centre of their focus and attention.

BARRY: *Well for staff, I think it's somebody who has a lot of time for everybody. Although they can be busy, I think a good member of staff is somebody who tries to speak to everybody and make them feel....a part of their lives in some way.*

Barry, interview 1.

The value of a trusted and reliable staff member who can be contacted for help at difficult times is generally out of all proportion to the work they will actually be asked to do. Often just knowing they are there is enough in itself to help people through.

ME: *How often do you see your Key Worker?*

IAN: *Oh, I'll see her a couple of times, two or three times a week. Or I can just give her a ring and she'll come over.*

ME: *And have you had the same Key Worker for a long time?*

IAN: *I've had the same Key Worker now for about two year. Er,.....but they do come and go. And when your Key Worker leaves, you get a new one and er,.....it doesn't take long to get used to her. But this one, Sylvia, is about the best one I've had.*

ME: *What is it about Sylvia that makes her so good?*

IAN: *Just the way she is. The kind of person she is. She's just like a sister to us. We can always carry on together. And, er,...she's close to us. We know each other very well. And I just get on very well with her. I feel safe and confident talking to her.*

Ian, interview 2.

DENNIS: *I mean, we've got tremendously good CPNs in this area. They're marvellous. They're available 9 to 5, Monday through Friday and they're very good, and we've known them, well, we've been here ten years and we've never had such support anywhere else. As Irene said, they're great. We're lucky that we've got such a good GP. He's great. He's a nice person and he takes an interest. Now we know him well so that, you know, if we run up the flag for help, he's there. But of course, at weekends, he may not be on duty, so you've got some third party, who may never have seen Irene and it's very difficult, given the nature of Irene's illness, to start at the beginning and explain it. You can't do it. I mean, it's just not possible.*

Irene and Dennis, interview 1.

ME: *Does it help that you've known him a long time?*

MATTHEW: *Oh, it does. Aye. You don't have to.....Oh. He just knows*

Matthew, interview 3.

These general, personal qualities were identified as crucial because they form the basis for the establishment of a trusting, honest and safe relationship between service users and staff. In addition people need to be able to access specialist staff who are both knowledgeable about the area in question and good at communicating with people.

ME: *What would you be looking for in a good psychiatrist?*

JOHN: *Two way communication, I think.*

LINDA: *Yes, because the majority of them are good listeners, aren't they? But they're not good communicators.*

JOHN: *No. And they don't tell you what they consider might happen....or effects of tablets and that, like.*

John and Linda, group interview 5.

HARRY: *Good staff talk to you and try to help you get better*

Harry, interview 2.

IAN: *Oh no, they're good like that. If I wanted to find out about anything like that, I would just get in touch with Liz, my Care Manager, and she would come over the next day and have a chat. She would have a chat and tell us every single detail.*

Ian, interview 1.

IAN: *She [psychiatrist] seemed to know what was going on. And that was it. I was here, in the hospital, because she had asked me those right questions, that nobody had ever asked us before. They hadn't asked the right questions, so I couldn't tell them. And now they can get us put right.*

Ian, interview 2.

ME: *I wonder what it is that makes somebody a good member of staff?*

BARRY: *The ability to communicate with everybody, no matter who it is. You know, to spend a little bit of time with everybody; to learn about everybody; to be interested in them as people. Not to just come into that room and start smoking and not really reach out to anybody.*

Barry, group interview 4.

The User Group at the Day Centre had discovered one way to start addressing these problems:

LINDA: *But that's good now, because we're involved in choosing the staff. So now we can communicate with the staff, which is great and makes it a lot easier. But before they wouldn't want to.*

Linda, group interview 2.

6.4 Actual staff

This section begins with a poem written by Carol Batton, which reflects many of the concerns raised by the participants in this study. It is taken from an anthology called "Only Connect" written by a group of mental health service users in Nottingham.

6.4.1 I'm Trained

Trained in what?
The pathology of schizophrenia?
The watch-your-back legal implications?
The "don't get too involved"
The "reflect back" non-response
of the person-centred counsellor
The "Sorry, I'm not in tomorrow,"
The "Why can't she improve for me,"?
The introduction via case notes,
The, "Sorry, it's a training day."?

Well, I'd rather have a friend, anyway.

The qualities and attributes outlined in section 3 were valued by all those interviewed. People spoke with deep fondness of good staff. They greatly valued their support and always remembered them with great warmth. However, they felt that experience of working with members of staff who displayed these qualities was all too rare and certainly could not be relied upon to be the case.

MARK: *An enormous and unwieldy so-called "team" has developed in place of any one person who knows about you, and nice thick files, with all the forms in triplicate, have taken the place of any real communication.*
Mark, interview 1.

If we were to visualise the ideal member of staff as someone who offers rapport and help; is knowledgeable about mental health and about you; listens to you; cares about you and is easy to contact; then actual staff do not often fit that template. They are difficult to contact; are pressed for time; keep office hours; keep changing jobs; may lack specialist knowledge; have conflicting roles; are not good communicators and can section you and want you to take medication.

Most of those interviewed recognised that it was the very nature of their jobs, or at least certain aspects of each of them, that made it very difficult for staff to be able to provide the sort of care and support that service users want. Current mental health services, through their personnel, rather than providing rapport and help in the areas that service users identify and in ways, places and times that suit them, as you might expect from a service that claims to be "client centred", seem rather to be based on an agenda determined by its professionals.

The times at which the relevant staff are available and the methods for contacting them are recognised as very important by service users for two reasons. Firstly, they know they need to spend quite lengthy periods of time with the same staff member, and on a regular basis, so that they can both get to know each other well. This time allows each service user to develop trust in, and understanding of that staff member, and enables the staff member to make more knowledgeable judgments about the service user's situation.

Secondly, because of the fluctuating nature of many people's mental health needs, they may be well on the day that the staff member visits, but then need to contact him or her urgently, and not necessarily within office hours, the following day.

Another problem for service users is the high turnover amongst staff and it can be a very distressing time for them when staff members leave for new jobs. In addition, where staff work in teams, it can be very difficult for service users to establish the kind of deep relationship that they feel they need with any one team member, or to feel confident that they will be able to contact the person they need at any particular time.

Therefore, a service which is genuinely able to respond to the needs of people with severe and enduring mental health problems must allow its staff to work with service users on this basis i.e. a small caseload of people with whom they can regularly spend time and who can easily contact them at any time.

ME: *Who do you find most helpful?*

MARY: *I think it all depends; who's there at the time. Sometimes you want your psychiatrist, and you can't get them. Sometimes you want your Care Manager, and you cannot get them. Sometimes you want your Primary Worker, and you cannot get them. So it ends as you're pleased to just get somebody.*

Mary, group interview 1.

JOSEPH: *He's [social worker] more elusive than the Scarlet Pimpernel.*
Joseph, interview 1.

ERIC: *It wasn't so bad before, when they [key workers] were based here, because you saw them all the time, even if it was only in passing, and so they had a better judgment on how you were. But now, you only see them...what? Once a ....Well, I see mine for five minutes once every three months. You know? So what chance is there?*
Eric, group interview 1.

ERIC: *Unless someone sees you all the time, they can't tell what you're actually like. So, you know, five or ten minutes or half an hour once every two or three months isn't going to do it. Like I said, by the time you're ready to open up and start talking about it, the interview's over. Or that's what I find anyway.*
Eric, group interview 5.

MARK: *If you were a nine to five lunatic, who took the weekends off, you'd fit the so-called professionals' picture perfectly.*
Mark, interview 1.

JOHN: *When there's a crisis the GP would be your first port of call, or the Samaritans, because they're the only ones who are there all the time.*

GARY: *But the thing is, as well, if you need the doctor in the middle of the night, you can't get them to come out. They'll not come out for mental health problems. The response I usually get is, "Well, Gary, I'm not here for mental health problems."*
John and Gary, group interview 2.

In general, the picture that emerged from the interviews was that the service users found staff difficult to contact, [this was especially the case for those people, and there were several, who do not have a telephone in their home] and not available at times like weekends, bank holidays and evenings, although mental health problems can cause problems for people 24 hours a day, 365 days a year. Even when the relevant staff member could be contacted, he or she could rarely spend as much time with the service users

as they felt they needed and saw them too infrequently either to have an accurate knowledge of their situation and condition, or to build up an open and trusting relationship.

The "enforcement" aspect of many staff jobs can conflict sharply with the need to establish trust and rapport which service users see as vital to any therapeutic relationship. It is very difficult for service users to talk openly and honestly about their situation if they fear that, by doing so, they may leave themselves open to being sectioned. The whole area of choice of treatments and of voluntary hospital admission is a particularly difficult one in mental health, overshadowed as it is by public fears of madness and political imperatives to be seen to be protecting the public. The fear of compulsory admission and/ or treatment hangs over all service users, not only those who have experienced it, and so colours the relationship between all service users and staff.

Even the most commonly used drugs can have very serious side-effects, which makes many service users apprehensive about taking them. ECT remains a very controversial and frightening treatment. Staff can then find themselves faced with an impossible dual role –on the one hand as an advocate and supporter of a service user; and on the other as an agent of social control. As people are rarely offered any treatment other than with drugs or ECT [see Chapter 7 on treatments] the staff's dual role makes it very difficult for them to have open and informed discussions with service users. Yet it is vitally important that these discussions do take place because people with mental health problems can often find themselves socially isolated and so have only staff members to whom they can turn for support and advice. [See Chapter 9 on self and others].

MARK: *You see, I was only seventeen when I had it [ECT]. And I tried to fight it always. But the nurse that was carrying it out was the Charge Nurse, who was always very parental towards us, in the sense that I was just a young lad then and he was like a father figure. He sort of....swayed us round....but I WISH he hadn't, because my memory's never been the same since that happened.*

Tim, group interview 4.

BARRY: *When I was in hospital, they gave us ECT against my wishes. I didn't want it, but there was no choice. They said that if I refused it, they would get my mother's permission; my mother's permission would be got off the Social Worker, and I would be forced into it. So they said I had better come quietly, literally, and getten it done. [Spoken quickly and urgently] It's like in shock.*

Barry, group interview 7.

Taken together, the short amount of time that service users can spend with staff, the variety of different staff members involved in their care, the problematic nature of the care they offer and their high caseloads make it difficult for staff to be what service users need: yet, because of the negative ways in which their mental health problems influence their self image [see Chapter 9], the manner in which staff interact with service users is crucially important to their well being. They must receive positive responses that convey the message that staff, at least, can still see them as valued human beings. As is clear from these interviews, when that is done, whether through laughter, jokes, instant practical help or a trip to the pub, it is highly valued and has an impact on people's lives that may seem out of all proportion to those whose own social worlds have not been thus shattered.

LINDA: *But Care Managers, they're meant to understand and to put a lot of work into it. But to me they don't seem to put a lot of....feeling.. into it. All they're thinking about is getting their paperwork done and gannin' to see the next user. Or getting users to go up to where they are, because it's easier for them then to see more people. Instead they should just concentrate; just sit down with you for ten or fifteen minutes and concentrating on that one person that they're with. They're all over the shop. They're thinking, "Well, that's it. Time's up. we'll have to go."*

Linda, group interview 1.

GARY: *It's funny that really, because they chose them jobs because they want to be a caring sort of person.*

LINDA: *I think it's with everything changing. I mean not just for the users, but the system for the Care Managers and the CPNs. they've just got that much to do, paperwork and stuff like that, that they just haven't got the time for the users, where they should be spending the time.*

GARY: *I wonder if it's partly the training though; because you go in one end one sort of person, and you come out at the other end and it's like you're a more stern kind of person.*

Linda and Gary, group interview 1.

ME: *What makes a good member of staff?*

DARREN: *A good personality, manners, respect for you. That doesn't happen often. Someone who'll listen to you. If I had a problem, I would contact my Key Worker. She's nice. She takes us out for a pint sometimes. And she's learned us to budget.*

Darren, interview 1.

IRENE: *She's [CPN] been so good to me, Marilyn. I can't explain it really. So nice. So caring to me. She's a really lovely lass. I don't know what I would have done without her.*

Irene, interview 2.

Listening and communication skills, both staff to service users and staff to other staff, are vital. Service users feel that many staff do not hear what they are saying, even though they may appear to be listening. This is a very disempowering experience, the equivalent of running into a brick wall: the person whose job it is to help you is present; you tell them what you feel and want; your words are either dismissed as misguided or translated, within the parameters of professional understandings of mental illness, into something quite different from your intention. Because the ideological frameworks and priorities of staff and service users are so different it is very hard for them to communicate. Just like British and American people, their communication suffers from existing within two cultures, divided by a common language.

ME: *What about talking to one of the nurses here?*

MABEL: *I've tried....I can't....I can't talk to them. I've tried, but I just can't. It's funny because I can talk to you.....but I just can't talk to the likes of them.*

Mabel, interview 3.

ME: *Do you have expectations about your new Care Manager?*

ERIC: *Well, I hope it can be better than it is now.*

ME: *In terms of?*

ERIC: *Listening, length of time, engaging.*

Eric, group interview 4.

This difficulty is exacerbated by the fact that your problems will be the concern of not just one professional but many within the mental health team. Although a team in name, their own communication problems, both practical and conceptual, have been highlighted in many recent reports, both national and local (Sheppard 1996) (Brown 1996). Service users are aware of these problems and are both confused and concerned by them. The fact that failures of basic communication between members of the team occur so often gives the lie to the suggestion, given in many of the Independent Inquiry Reports (Sheppard 1996), that they occur only in these exceptionally difficult cases. Although it is only these cases that are given thorough surveillance, it would be a mistake to conclude that these mental health services were delivered in any different way from the norm or that any spectacular and unusual mistakes were made: rather, these cases are but one point on a continuum and within one dominant ideology of people with mental health problems and their "care".

ERIC: *All your Care Manager goes off is the reports of other people, because they don't see you that often to do anything else. I've got to go to the doctor's tonight. I don't know whether my doctor will put in a report to my Care Manager or what. You don't know who knows what here really.*

Eric, group interview 1.

GARY: *It's just back to lack of communication, isn't it? You tell all the different people, but you know yourself that there's nowt they will do. Different professionals don't communicate with each other and they don't listen to you. They only hear what they want to hear. Like when I came out of the rehab programme. I went in one end of the system and came out the other feeling no better at all and with no-one to talk to. Neglect in the community. Yeah? All I got was a weekly chat with my Key Worker and they would just say, "Oh, you're doing really well now. You're self-medicating." And I was sitting there thinking, "I'm doing really well," but I'd be feeling horrible. I just wanted to die.*

Gary, group interview 2.

BARRY: *I've given up with the doctor like. I used to see the doctor or GP but I've give up with them now. You know? I cannot be bothered to keep going through it. You have to keep on explaining everything to a different person each time. It's not nice to keep going through it all. And they just pass you off. Dr. T. says ,"See your Key Worker." And then you come here and they say, "No, see your doctor." So you get bundled around back to your doctor. He says, "Nope, your Key Worker." And so it goes on.*

Barry, group interview 2.

The problems already highlighted in this chapter make it hard for staff to provide what service users want even if they stay in post for long periods of time. In the current mental health system, which is still in the process of change and still of low status, most people will experience a constant and rapid staff turnover within their team.

DENNIS: *For Irene to tell the story that she has to tell.....well, she wouldn't want to tell it to a complete stranger.....umm, there's very few people have ever heard the whole story, have they?*

IRENE: *No.*

DENNIS: *And that would be, the CPN, Dr. C. and myself.....that's about it really. To involve outsiders doesn't help when Irene's having her problems. She wants to be with friends. Or people who understand her, who don't need to ask questions about how do you feel and all the rest of it. And it's that continuity which ought to be somewhere built into the terms of reference of community care. There is this need.....You can't be bounced from one doctor to another, from one nurse to another nurse.....somewhere in the system, whether it be via the CPNs or via an asylum type of place or the two mixed in together, we've got to have continuity of care, because continuity of care, in the case of Irene's type of illness, is essential.*

Irene and Dennis, interview 2.

ME: *What about your psychiatrist?*

PAUL: *He's alright. Mind, it's not often the same one. They disappear. It depends on his er,.....practice. I only see him about every six months. I've seen one just recently and he was okay. But I don't know how long he's going to be here like! And then you have to go through it all again.*

Paul, interview 2.

There were many complaints about GPs' lack of knowledge about and interest in mental health. Given that they are the gatekeepers to the specialist services and the easiest professionals to contact, this is unfortunate.

CAROLE: *I've made an appointment to see my GP tonight.*

ME: *Will that help?*

CAROLE: *No! They're no good. No good at all. They don't know about mental health.*

Carole, interview 1.

However, even once the initial obstacle of the GP has been overcome, there are still gaps in expertise. It was rare for someone to have found, and kept, a mental health professional who was sympathetic to, and knowledgeable about, all the aspects of life with a mental health problem that were important to service users.

LINDA: *They [psychiatrists] can understand the clinical side, but they don't understand the emotional side. You need a user for that.*

Linda, group interview 1.

ME: *What does the Care Manager do for you?*

TIM: *[silence. giggles.] Umm.....well, he's very good at talking. He would talk to you for ever and a day about your emotional problems, or your depression, you know? But I've never found him any good in practical issues. Umm....and I have had practical issues that have affected my mental health.*

Tim, group interview 4.

6.5 Discussion

Consideration of this material from the interviews highlights a number of gaps and dilemmas that face service users in their interactions with staff in the mental health services.

The gaps occur where the priorities of service users are not those of the staff who are there to help and support them. Indeed that very phrase begs the question; what constitutes help and support for a person with a severe and enduring mental health problem? Many Health Service staff may be working within a different framework of beliefs about the aetiology, course and best treatment of mental illness from that of their clients/ patients (Rogers & Pilgrim 1997).

Staff, viewing mental health problems within a disease/illness model, may see their role as being to provide treatments which will relieve symptoms, such as visual or auditory hallucinations, through a set code of service delivery and within a relationship which privileges the expert knowledge of doctors and nurses. For example the NHSME in 1996 recommended that for people with severe and enduring mental illness:

> staff will need the specialist skills to meet the demands of this client group. In particular, they should be capable of assessing symptoms, dispensing medication, dealing with challenging behaviour and continuously monitoring the risk of suicide, self-harm and violence (NHS Executive 1996).

Service users, viewing mental health problems within a social/ discrimination model may want to receive support in a number of areas of their

everyday lives, in whatever style best suits their individual needs and situations and in a relationship of partnership that gives equal value to their knowledge. For example Beeforth et al. in a study examining service users' views on case management found that:

> knowing that the case manager was reliable, readily available, willing to tackle a problem about a bill or a difficult negotiation about medication, and to provide a therapeutic listening ear, gave people the confidence to tackle the challenges of living in the community.....What the majority of people valued most of all was the relationship with the case manager (Beeforth, Conlan & Graley 1994).

In addition, staff working in the field of mental health face extra pressures because of the legal and social concern with their role. These continuing pressures have been reflected in recent newspaper reports: for example, Peter Morrall was quoted in the Observer, 19.4.98., addressing the annual conference of the Royal College of Nursing thus:

> Psychiatric nurses must abandon fashionable patients' rights theories and concentrate on their traditional role –policing the mad. The job should be about mopping up deviant behaviour and protecting the public and the patients (Morrall 1998).

Whilst Dawn Wakeling, from the Mental Health Foundation, writing in the Guardian three days later, summed up the results of her research with service users as:

> above all, they wanted someone to talk to who would listen (Wakeling 1998).

Given these gaps between what service users want and what staff are able to provide, the dilemmas that anyone with a severe mental health problem must attempt to resolve are made more extreme. People with mental health problems want help. Family and friends may vanish with the onset of mental ill health [see Chapter Nine; self and others]. Therefore staff are a more important source of help then they may be in other types of ill health. To get access to this source of help people must agree that they have a mental health problem. This admission carries a high cost in terms of people's ability to continue living in their social community. Yet, having made this admission, they may find themselves still unable to access the help they feel they need, and may even feel that their situation has worsened.

As we have seen from earlier chapters of this thesis, problems with staff are by no means a new feature of mental health services. However, since the voice of service users themselves was rarely heard before the 1960s, these earlier problems were framed by policy makers and professionals and focused on the difficulties of recruiting and retaining staff with the necessary qualities and characteristics in jobs that were so demanding and yet offered such low rates of pay and social reward. Today much the same difficulties remain. although, perhaps, today's mental health professionals would not be quite so dramatically described as:

> the unemployed of other professions....if they possess physical strength and a tolerable reputation for sobriety, it is enough; and the latter quality is frequently dispensed with. They enter upon their duties completely ignorant of what insanity is (Busfield 1986).

Nevertheless, because of the national shortages of trained staff, it has been difficult to implement some of the planned changes, and staff from the long stay hospitals have been re-employed in community settings, without the necessary retraining or selection of those with a community orientation. However the underlying problems, outlined in this section, would still remain unresolved, as exemplified by this extract from the 1997 advertising campaign aimed at attracting people into mental health nursing:

> Could you help someone get rid of all the cockroaches on this baby? The bugs do exist, but only in the mother's head, and it will take all the specialised skills of a mental health nurse to get them out of there.
>
> To begin with, the nurse needs to persuade the woman that her baby is perfectly normal. Other people can help, but it's the nurse who the mother will come to trust. She'll trust her enough to talk about her deepest problems. Or enough to take any medication the nurse thinks is necessary.
>
> Gradually the apparitions will disappear. Little by little the mother will recover. Would you have the sensitivity and patience to help someone like this? Could you win her trust? or work with her family every day, until she recovered?

On the evidence of these interviews, which resonates with and adds to that from other service user based research (Northumberland Health and Northumberland Social Services 1996) (Rose et al. 1998) (Murray, Shepherd, Onyett & Muijen 1997), this picture of mental health nursing is also an

apparition, for both staff and service users. For example Shepherd et al., in examining service users' views on services for people with schizophrenia in the community, found that:

> in general, the attitude towards most mental health professionals on the part of most users could be described as, at best, ambivalent. Professionals were seen as potentially valuable, but too often preoccupied with their own agendas and not really in tune with users' perceived needs (Shepherd, Murray & Muijen 1994).

A view which echoes that found in Barham and Hayward's study:

> In participants' experiences of services, the significant questions that concerned them about the value and direction of their lives were left unaddressed or obscured (Barham & Hayward 1991).

Even studies whose main concern has been to increase service users' compliance with treatment regimes and contact with services have found that high quality relationships with staff are a major factor in success (Howlett 1998) (The Sainsbury Centre for Mental Health 1998).

It may be that, in any field of ill-health where the condition will endure over long periods of time and can't be cured, [exactly those areas which are now the major concern of the health service], we need a new "story" of medicine and healing; what Turner describes as a move away from scientific medicine[monocausal disease, germ theory, medical model, heroic medicine] towards social medicine [multi-causal, strong social component, interdisciplinary approach] (Turner 1992). Where professionals cannot offer a cure, their healing must lead to an acceptance of life with an illness, but a life that still has worth, value, joy and pleasure. Hannigan et al. in a study examining service users' perspectives on improving health and social functioning, found that they would give pride of place to:

> the importance of practitioners developing and maintaining high quality interpersonal relationships with users. Our data suggest that users clearly perceive trusting, confiding relationships to be inherently health-promoting (Hannigan, Bartlett & Clilverd 1997).

All too often this emphasis that service users place upon the personal qualities of staff is disregarded and dismissed as a misunderstanding on their part. Instead it should be acknowledged and nurtured as the sine qua non of effective working relationships between service users and staff. It is crucial that mental health staff have empathy with and commitment to service users

and a willingness to work openly with them and to value their knowledge and experience of their own situations. Marion Barnes has discussed the importance of this style of partnership working, explaining how it can not only lead to improvements in terms of providing more effective and acceptable services and support but is also "transformative" (Barnes 1997). By this she means that it changes the ways in which staff think about service users and their situations and changes the ways in which service users think about themselves; no longer as passive recipients of services but as valued partners in problem solving and service development.

Until such a new story is established and accepted, staff as well as service users continue to interact, as they have for centuries, within competing contradictory and, ultimately, unsatisfactory pressures and the "shape" of the staff provided by those driving mental health policy will continue to be the wrong one to adequately fit service users' perceived needs.

The final words of this chapter are theirs:

ME: *What does your Care Manager do for you?*

LINDA: *Not much!*

ME: *Is that what you expected?*

LINDA: *[laughter] I didn't expect it and I didn't want it! I thought it would be completely different. But it's just a system thing that you get sucked into. Everybody does.*

Linda, group interview 1.

ME: *Is that what you expected from a Care Manager?*

GARY: *Well, it's not what I originally expected. I used to think that it would be somebody to talk through all your problems with. But I've found that's not really the use for a Care Manager at all.*

ME: *What has its use turned out to be?*

GARY: *Just to sit and have a laugh and a carry-on and that –and give me my injection basically. For twenty minutes! [hollow laugh] Once a fortnight! And I'm one of the lucky ones!*

Gary, group interview 4.

ME: *What do you think makes a good member of staff?*

IAN: *A happy person. I think that's the most basic thing you need. Because somebody who's....strict and miserable isn't going to work wonders with the patients and get on with them that well. But if they're happy and got a good sense of humour, that could be their saving grace, because they can learn all the rest.*

ME: *So it's the personality that's most important?*

IAN: *Yes.*

Ian, interview 1.

7. KEEP TAKING THE TABLETS: SERVICE USERS AND TREATMENTS

7.1 Introduction

This chapter outlines and examines the participants' experiences of, and views on, another topic that arose in all the interviews; the treatments on offer for severe mental illness.

It is not altogether easy to define what constitutes a treatment in this context. When participants were talking, their definition seemed to include only medical treatments, such as tablets or injections. Professionals might want to include anything offered with a therapeutic intent, such as time at a day centre or employment scheme.

The initial coding of the interview transcripts aimed to adhere to the participants' definition and so all material including discussion of treatment in their terms was stored under node 2.1.3. In addition, all the transcripts were string-searched for the following words and phrases and the results of each search stored as a separate sub-node:

- 2.1.3.1. needles and injections;
- 2.1.3.2. drugs and tablets;
- 2.1.3.3. ECT, electric treatment, shock treatment;
- 2.1.3.4. side-effects, information;
- 2.1.3.5. medication;
- 2.1.3.6. section, sectioned, sectioning, sections;
- 2.1.3.7. treatment;
- 2.1.3.8. therapy;

- 2.1.3.9. cure;
- 2.1.3.9.1. better, improved;
- 2.1.3.9.2. help, helps, helped.

Having re-read all the material in these nodes, it was again apparent that there was a gap between what people had hoped would be available to them when they first became ill and what they had since learned about the treatments on offer.

Consequently this chapter employs the same structure as the previous one in that section 2 begins by discussing the participants' ideas on ideal treatments. Section 3 contrasts these hopes with their concerns about the actual treatments offered. Section 4 concludes the chapter by discussing this gap between ideal and reality and highlighting the difficult dilemmas that service users consequently face in their decisions about whether or not to comply with treatment regimes and the many repercussions of these decisions.

7.2 Ideal treatments

There was a clear message from the service users about the type of treatment they had hoped for when they first became aware of problems and sought help from the mental health services.

They were expecting a medical treatment that: would provide a complete cure; without any side-effects; and be delivered in a way that allowed them to feel empowered and retain their self-esteem.

BARRY: *And the other side of that would be medication. There was always going to be some wonder drug. There was going to be some tablet that would cure all your problems. And so they would push a lot of medication on to you. My expectations then were different.*

Barry, interview 1.

DARREN: *I just have to hope that some new treatment, or cure, will be discovered so that I can stop taking all this medication.*

Darren, interview 1.

GARY: *You're always waiting for the magical thing to happen; but it doesn't. You're waiting for somebody to help to pull you out of it. When I first went into hospital, I thought, 'Well, there's all these professionals here and obviously...hopefully....somebody's going to be able to do something for us, to pull us out of it."*

Gary, group interview 2.

IAN: *Well, I always hoped that they would find a cure. But now I know that they'll never find a cure in this day and age. Not for what we've got. It's too complex. Everybody's different.*

Ian, interview 1.

MATTHEW: *When I first got ill, I thought then that I would get completely better like. But I've got to have the injection now for ever, because, if I ever came off them, it will come back again like....what was happening to us. It would come back likely enough, if I came off the injections.*

Matthew, interview 3.

7.3 Actual treatments

Once again, people's initial hopes and expectations about the help that mental health services could provide for them proved to be a poor fit with their actual experiences. The treatments available could not offer a cure and had many serious side-effects.

All the people I talked with during this study had been in contact with the mental health services for many years and most had experience of a variety of different drugs and of ECT. None of them any longer expected to be cured, although some still had hopes for a drug-related breakthrough in the future.

CAROLE: *When I first saw the psychiatrist I asked him, "Can you cure it?" And he said, "No, but I can control the symptoms."*

Carole, interview 2.

DARREN: *I know there's no cure.*

Darren, interview 1.

IAN: *You always have a relapse. You always do with this illness. Even if it's years and years and years. It always comes back for you again.*

ME: *You don't expect to be cured?*

IAN: *No. No. You can't be. It's not cure; it's prevention. I've seen some of the best people go out for years, maybe twenty years, and then they've had to come back in again. It does; it just creeps up on you. You get unwell, and then you have to come back in again.*

Ian, interview 1.

IRENE: *I don't know if I'm being pessimistic, or negative even, but I don't think you can CURE a mental illness. I think, once it's happened, it's everlastingly with you, and I think the only thing you can hope is that there are people around who can alleviate the pain of it.....because I don't think I shall ever be rid of my particular....um, illness. I don't think it will ever go completely from me. I think it will always be there. I don't think anyone will ever take that away from me and make me feel...er, -whole..*

Irene, interview 2.

Against this background there was no one service user view about the treatments they had experienced. Indeed, not only did different people hold different views, but also people's views might change over time. Nevertheless, there were common areas of concern about the treatments available and everyone was working through the same type of risk/ benefit calculations for their particular situation, whatever decision they finally took.

A very large consideration in these calculations was the side-effects that most people experienced as a result of taking medication, and the important side-effects of these side-effects on their lives.

ME: *So, looking back on it now, do you think the drugs have helped at all?*

BARRY: *Oh, that's difficult....you see, I don't like the drugs in a way, because they're physically destructive.... they don't destroy you, but they .....they do things to you, like make you fat, that make it hard to live and go out, and you get depressed and worried and slow, so they destroy your life anyway.*

Barry, interview 1.

CAROLE: *You see, she put me on Lithium about three years ago. She said, "Now I want you to have a go on Lithium for a few months." Well,...now it's years since I've been on these, and, if the truth be known, I think that some of these tablets are making me high. Making me worse, not better. It's no good, you know.*

Carole, interview 1.

JANE: *Oh yes, he's very keen on Lithium alright [the psychiatrist], but not me. I often wonder where I would be now if I'd agreed to have a course of Lithium. I think about all those poor, unfortunate people who've been through courses of anti-depressants and Lithium and all the rest of it, poisoning their systems with these chemicals, when, in fact, it's within one's own head and heart to sort it out oneself. That is how I feel, because I could have been POISONED by that. I could have had kidney failure. I mean, there's a list as long as your arm of contra-indications in that book [BNF] but they would never have told me that. Why does our blood have to be tested at regular intervals? Because it's a chemical, a poison. Eeh! Keep it to fireworks, that's what I say!*

Jane, interview 1.

The side-effects most commonly mentioned during the interviews were weight gain, uncontrollable shaking, extreme agitation, choking sensations, feeling slowed down and tired, feeling nauseous and dizzy and experiencing a loss of sex drive. Experiencing these is very unpleasant in itself, but they also have the effect of making it more difficult for people to maintain and participate in an "ordinary" life.

As people's hopes for a cure disappeared, they were rapidly replaced with fears about the treatments on offer. In addition, many people had to take extra drugs to combat the side-effects of their primary treatments. They could thus find themselves ingesting, on a long term basis, a daily cocktail of different drugs whose cross-effects may have been little researched. This added to their anxieties about whether to comply with the treatment regime. Their everyday lives became dominated by drug taking.

MATTHEW: *Well, the tablets weren't doing us any good. They were making us drowsy like, you know? Tired all the time. So the doctor took us off them, and I feel alright now with just the injection. But the trouble is that I get side-effects from the injection, so now I've got to take tablets for the side-effects. I take these all in the morning and they keep us right.*

Matthew, interview 3.

DARREN: *I hate drugs!! They give me terrible headaches, and they've slowed us right down. They make me feel bad, sickly. So then they have to give you another tablet, for them side-effects. And they never tell you. They're testing them on me, I think. It's cruel. I practically live on injections and tablets; they're my food. And those injections are dangerous too. You have to be careful how they give them. It could paralyse you, if they hit a certain nerve. I'm pumped up with tablets all the time. I have fourteen tablets a day, morning and night. I pour tablets down my throat for breakfast. It slows you down, man. It's killing my brain cells.*

Darren, interview 1.

The experience is often made worse by the fact that people did not feel that they had been prepared for these side-effects and were not warned about the possibility of them when starting on any medication. This not only made experiencing them even more frightening but also had a deleterious effect on people's relationship with their clinical care giver. They felt they had been tricked into taking the medication and so were less willing to trust the care giver's advice on future occasions.

ME: *Were you told about the side-effects?*

CAROLE: *No. They never tell you.*

ME: *You don't get any leaflets or other information?*

CAROLE: *No, no leaflets. Nothing like that.*

ME: *Does she bring your notes, or your care plan, or talk to you about your treatment?*

CAROLE: *Why no! Nothing like that. You just go into that hospital and they put you on tablets and that's it. And they forget all about you once you're back home.*

Carole, interview 1.

ME: *Did they tell you you might get side-effects from them?*

MATTHEW: *No. No. They never said anything about them. I was just getting them like, you know, from the injection. So, when I saw the doctor, I said to him about them, and he put us on these tablets.*

ME: *So you hadn't known what to expect?*

MATTHEW: *No, it just happened.*

ME: *So what did you think, when the side-effects started?*

MATTHEW: *Well, I didn't know what to think really like. I didn't know what it was.*

Matthew, interview 2.

ERIC: *What you need is a breakdown of the drug –what its side-effects are, what it does, what other names it's got, so that at least you would know what you're taking. Some of these tablets make you sleepy, some make you dizzy, others can make you sick.....and if you haven't got this information when you take the tablets, and you suddenly get the symptoms, you think there's something worse wrong with you!*

BARRY: *Yes, they do patronise you. They say they're going to make you feel better, but they won't tell you what's in them.*

ME: *Doesn't the Charter say that you're entitled to clear explanations and written information about your medication, including any side-effects?*

ERIC: *Yes, BUT, a lot of people, when they get their medication, wouldn't think to ask, would they? You're too uptight to start with, and things just fly out of your head.*

JOHN: *That information ought to be given because, when you do have a side-effect, the symptom can seem to be far worse if you've not been told about it. Then you can put up with it, if you know and it's not too harmful.*

BARRY: *Well, when I took Trazodone I read a book about drugs and their side-effects. And I did get the side-effect and I told my psychiatrist and he took us off it and the side-effects went away. But if I hadn't read a book about that, you see, and he didn't tell us, I wouldn't have known what was happening and I would have been very frightened. But I knew it was the drug.*

Barry, John and Eric, group interview 3.

GARY: *Yes, the doctors need training, in other forms of help like. And the drugs. Well, they do know about the drugs, but they won't tell YOU about it. As far as the side-effects and all that are concerned. They don't tell you. Well, I mean, like, I get all kinds of side-effects, but when I was first put on to medication, I was told I might shake a bit, and that was it. I've never been told anything else since. I'VE had to find out about it and then ask the doctors what they think about it.*

Gary, group interview 1.

Although staff may think they are providing information about treatments, choices and side-effects, this is overwhelmingly not the impression that service users themselves have. Consequently, whatever the "facts" may be, the objective is not being achieved and better ways of imparting this information still need to be developed.

The side-effects from medication can be serious and disabling in themselves, but they also have serious quality of life implications for the people who have to take them (Howlett 1998). Rogers, Pilgrim and Lacey, in their survey of users' views of psychiatry, describe them as both "life diminishing and life threatening" (Rogers et al. 1993).

The dilemma that service users must attempt to resolve when deciding whether to accept drug treatments is that doing so may cause what they hope to cure, not only in physical terms through things such as agitation and hallucinations, but also socially through exacerbating their social isolation and exclusion. People who feel fat and tired find it harder to join in the usual social activities, and those who shake and shuffle are often shunned by their communities (Estroff 1981).People may know that they need the medication in order to continue to function in their social community, but its side-effects may nevertheless mark them out and reveal their mental patienthood and thus still lead to their exclusion from that community. It may cause them to suffer what Nicholas Fox has described as "a premature social death" (Fox 1993).

IAN: *Then I got a job, farming. It was really good but ....I was getting tired. It was hard work and I was getting more and more tired....And it was good money and I was having a good time...But I had to pack it in because of the Clozapine. I was on a tablet called Clozapine. It was a new tablet. A wonder drug they called it for schizophrenia. But the problem is, you've got to have your blood tested while you're on it, because it does something to your white blood cells.....[stuttering]....it makes less of your white blood cells, so you're more prone to infections. When mine went really bad, below the white blood cell count, I had to come off it, and I had to pack my job in on the farm.*

Ian, interview 2.

It would seem that many clinicians do not fully appreciate these problems, since recent research shows that they tend to underestimate both the frequency and the severity of the distress associated with the common side-effects of neuroleptics (Hughes, Hill & Budd 1997). Such distress may not be simply from the physical unpleasantness of the side-effects but also from the meanings that people attach to them for their views of themselves and of their future life.

7.3.1 Lack of choice [and information]

Many of the participants complained about the lack of choice of treatments. This has two aspects. Firstly, there is an extremely limited range of treatments offered. All the people in this study were either given no choice at all or asked to chose between a drug treatment and ECT.

ERIC: *I'll see my doctor once a month, or whatever, and he'll say, "How are you feeling? Any better?" And I'll say, "Depression's been bad," or whatever, and he'll say, "Oh, right, increase your medication then." And that's it!*

Eric, group interview 1.

ME: *Does he ever suggest any other kinds of treatment?*

ERIC: *Not really, no.*

ME: *Could you suggest anything to him?*

ERIC: *Umm... No. Because, to tell you the truth, I don't know exactly what's available, and that.*

GARY: *Yeah, and that's another thing, isn't it? You don't know what is available.*

LINDA: *But we know what isn't available!!*

Eric, Gary and Linda, group interview 1.

Despite their very different backgrounds, situations and individual preferences, people were all offered very much the same treatment response–drugs/ ECT, and only drugs/ ECT,–whereas what they had hoped for was to make an informed choice, in partnership with a known and trusted professional, from a range of services including alternatives to medication that made allowance for their own individual path to recovery (Chadwick 1997).

MARK: *Rehabilitation and care are important, as well as drugs, but we were just pumped up with drugs and left to get on with it.*

EILEEN: *And I was completely excluded from Mark's care. I felt I really understood what his problems were, and went to a great deal of effort to get them written down and handed over quickly. But they were just consigned to a thick wadge of papers and disappeared. It seemed as if I was just ignored.*

Mark, interview 2. [Eileen is his wife]

ERIC: *You just end up on a heavier dosage, you know. It seems like the whole thing's just medication.*

GARY: *Yeah...What we're saying is, people don't realise that there is other like forms of help.....I mean, this new cognitive therapy,...I don't know how new it is like.....but there's that. It probably costs a lot of money for people to have cognitive therapy, but I'm sure that can help. Just as well as medication. I'm sure it can.*

LINDA: *But we're not getting that information though.And we're probably not getting that information because it costs that much money to do it.*

ERIC: *But look what it costs every week in medication. But that's the easy answer, medication. Once you....I knew that once I got onto medication that would be it. I would be on medication all the time after that. And that's what's happened!*

LINDA: *Yes, it's a vicious circle isn't it?*

Eric, Gary and Linda, group interview, 1.

BARRY: *There needs to be more emphasis on people.....um, because, like I said before, everybody's illness is different, and what works for one person doesn't work for someone else. It's a difficult job to try and diagnose and help when everybody's got different problems. It's not like treating people with broken legs, where the treatment is all basically the same. When people have got broken minds, or broken spirits, then the way of treating them has to be completely different. There's not one method that will do it for everyone.*

Barry, interview 1.

Many of the recent Independent Inquiry Reports into homicides committed by people with a mental illness have highlighted the importance of this gap in the system. For example:

> The second fundamental flaw that afflicted the actions and omissions of the professional carers of Andrew Robinson was the dissociation of psychiatric treatment from the social context in which care must be delivered in order to be therapeutic (Blom-Cooper, Hally & Murphy 1995).

It was also acknowledged by the Royal College of Psychiatrists in their Manifesto for Mental Health.

> We are not making full use of proven therapies and techniques which can benefit patients. There are a number of interventions including cognitive psychotherapy, short focused behavioural interventions and family interventions in schizophrenia which have been demonstrated to be effective. Yet, in many areas, patients have little or no chance of getting access to these (Royal College of Psychiatrists 1997).

The second aspect of the lack of choice that people experienced was whether they then had any real choice about whether or not to take the offered treatment.

This may be because of the power imbalance in their relationship with their clinical care-giver.

CAROLE: *I'm sick of getting them, Marilyn, but it's for your own good, they cry, and that. Oh dear!*

ME: *So it would be difficult to say you didn't want it?*

CAROLE: *It would, yes, because Ruth [CPN] comes here and....if I say to Ruth tomorrow morning that I want to come off it like, she'll say, "And I know where you'll end up, Carole! Back up in that hospital!" That's what she cries all the time. So it's hard really. Oh dear!*

Carole, interview 1.

ME: *Did the ECT help?*

CAROLE: *No! No way I would get that again, Marilyn.*

ME: *Why's that?*

CAROLE: *It er,...well now, I'm ill when I get that. Aye. Yet, according to her, to Ruth [the CPN], it makes us better. Eeh! "Now", she says, "Carole," she says, "you have the electric treatment. It's good for you. Does you good." No way I would have that again! I had six. No way!*

Carole, interview 1.

DARREN: *I'd love to leave this hospital, to go home, but I know what would happen if I walked out. Last time I was pinned down. Two big blokes got us and gave us an injection. They were kneeling right on me. I would love to go home, but if I go they'll just slap a six month section on me. But you're better off at home. They should all be at home with their mothers and fathers, and take their tablets there. It's not natural to separate families. It's cruelty. They shouldn't be here, where you don't know anybody, and you get hit by patients with big rings on. They should shut all these hospitals down.*

Darren, interview 1.

ME: *Is it hard to say no to medication when it's offered? Did they accept your decision?*

JANE: *I think they accept it.....BUT, I think they accept it reluctantly. And I think they would rather that I took it, because they would feel that it would make their job easier if I took it.*

Jane, interview 1.

In these situations it is very hard, emotionally or physically,to question what is on offer. Service users may not only be working within a different

paradigm of mental distress but are in a vulnerable situation where they may also be wary of jeopardising an existing, if unsatisfactory, relationship [when they have so few in their daily lives] and their gateway to even such services as are on offer.

People may also feel that their individual choice is curtailed by the competing demands of other users.

LINDA: *And they always seem to be pushing you on. You see them once a week, and then they think that you're looking a little bit better, so we'll put you on to once every other week; and then it's once a month, and then it's once every two months, even though you're not ready for it. I mean, you might be feeling great one month and down the next, but they're still slowly getting rid of you.*

ERIC: *It's, "Now, you know what you've got to do. I don't think these sessions are helping any more." Just because they've got other people coming on all the time. So you're just left high and dry.*

LINDA: *They've got too many people on their caseloads.*

Linda and Eric, group interview 1.

These concerns limit people's choices in all areas of the Health and Social Services. However, in the field of mental health, users' "choices" are always overshadowed by the spectre of compulsory treatment.

BARRY: *It's difficult for me to talk about it really. It was a long time ago.....but I've had ECT. I said to the doctor, "What will happen if I don't want it? I don't want ECT. What would happen if I refused?" "Well," he said, "we'll get your mother round here and she'll sign the form, and I'll sign the form, and you'll be forced to have it. So," he said, "we'd much rather you volunteered."*

Barry, group interview 3.

GARY: *I was at a conference over the week-end and they're doing something about compulsory ECT and trying to ban it. But, I mean, there are times that, even if you're carrying a crisis card or whatever that says you don't want ECT, it doesn't matter what you want at all. They can just give you compulsory ECT. Disregard your wishes altogether.....It's so shocking that.....frightening....when it's you.....*

Gary, group interview 5.

MARK: *And you're in an even worse situation when you have a mental problem. You're very vulnerable. They can dangle a section over you, as a threat.*

Mark, interview 2.

ERIC: *Yes, there's always that worry at the back of your head. If you keep on saying no, are you going to get sectioned?*

Eric, group interview 4.

These fears were echoed nationwide in a survey into service users' experiences of ECT conducted by the United Kingdom Advocacy Network which showed that three quarters of respondents felt they had been given inadequate information and more than a quarter had been threatened with a section if they did not agree to have ECT (United Kingdom Advocacy Network 1995).

People's real choices are also limited by the paucity and quality of the information to which they have access.

All the concerns raised thus far are in direct contravention of the statement of rights concerning treatments given in the "Health of the Nation" booklet on mental illness, which states:

> When you are being treated for mental illness you are entitled to –a full explanation of possible side-effects before taking any drug; –a full explanation of what ECT involves before treatment; – discuss what alternatives to drugs or ECT are available (Department of Health 1995*d*).

and of the Guidelines for mental health and learning disabilities nursing issued by the UKCC in 1998 (United Kingdom Central Council for Nursing, Midwifery and Health Visiting 1998), and of the local charter for users of mental health services (Northumberland Health and Northumberland Social Services 1996).

In situations like these, with such limited choices and information, can people really be said to be giving their informed consent to treatment?

7.3.2 The process of receiving treatment [and information]

As this picture of being on the receiving end of treatments for mental health problems emerges –that it cannot offer you a cure, that it can have devastating side-effects, that you feel you have no choice of which treatment to have

or any involvement in the decision to have any treatment at all–the final blow is the way in which such treatments are delivered.

MARK: *But as far as actual understanding goes, of the illness or of its treatments, it's still dehumanising to those who are suffering from the most horrendous things. In terms of quantity and quality it has actually got worse.*

Mark, interview 2.

Taking their medication often becomes a major part of people's lives once they have a mental health problem and many people find it a very unpleasant process that leaves them feeling disempowered and fractures their self-esteem.

Given that drug treatments are often the only option available, people generally prefer to take tablets rather than suffer the added humiliation of receiving injections.

ME: *What is it that you don't like about injections?*

IAN: *I just don't like believe in.....the rigmarole of going through an injection every week, or every few weeks. Being a patient. I believe it's wrong. I believe they should be on a medication that's .....easier for them. Because they've got enough troubles to solve. They don't need one of those big, long needles stuck into them. Because they're painful. I've always believed that. .....I believe they should be on tablets all the time. Instead of giving people injections, they should have more..... modern medication.*

Ian, interview 1.

GARY: *Well, I don't like needles. No. And, er, ...once you've got that injection inside you....I mean. They said it was going to be for a month, and once it's in there, there's not a lot you can do about it. Plus, I mean, I was ill at the time and all these things were frightening us like. So, I mean, the only choice in the end, that I wasn't given but I made by myself, was to get my injections like fortnightly instead of monthly. I wasn't given that choice. I had to ask if I could have that choice. So luckily I knew at the time that I could make that decision. People just think that it's got to be in monthly, you know.....you're not really educated about these things.*

Gary, group interview 1.

MATTHEW: *Well,.....I don't really mind the injections now like. I've got the hang of it now. You've just got to take it, what you need. I did stop them once, and I just took bad again. So I've got to have them, whether I like it or not.*

Matthew, interview 3.

The depot clinic may be a convenient way for staff to dispense drugs to many service users and to ensure that they are complying with the prescribed regimes, but for most people they form part of an alienating practice that may in fact rather contribute to non-compliance and people being lost to the system altogether. The picture that many people painted was of a difficult journey to an institutional and medical setting, followed by a long wait in depressing surroundings for brief contact in sensitive circumstances with unfamiliar and uninterested staff (Rogers et al. 1993).

Many people also spoke of their fear of ECT, a fear that often shaped their "choice" of continuing with other treatments.

IAN: *And then he asked us lots of questions about whether I wanted to start on medication or the electric shock therapy. Then he told us all about the electric shock treatment. And then he told us about the tablet form of medication. And I signed for the tablet form. I didn't want the electric shock treatment.*

ME: *Why was that?*

IAN: *Well,....I didn't like the sound of that. because they put you to sleep. It's frightening. They do things to your head, to your brain, while you're asleep. And when you wake up you don't know where you are and that.....*

Ian, interview 2.

Many people felt they had no choice about when or how to receive the offered treatments, and this could adversely effect other areas of their lives.

MATTHEW: *I'm trying to come here [sheltered workshop] five days a week now because I'm.....well, the only reason I was coming here four days was because I got my injection on a Friday, every fortnight, at the doctor's. But now they've decided to change it and I get my injection on a Tuesday. So I can finish work and go down to the doctor's then. So I'm going to see if I can get the Friday as well, because I've nothing to do on a Friday. It's boring sitting in the house like. Everybody else is busy.*

Matthew, interview 2.

Most people had regular contact with staff only when receiving treatments. For many this militates against their being able to establish with them the kind of relationship that they would find most helpful. [see Chapter Six, on staff]

IAN: *Well, I get up early and have a smoke, and I might have my tablets and then go back to bed until half past eleven. Then we'll have our morning medication at the staff house and come back here. We would maybe go to the gym, or sit and watch the tele. or have friends in.....it's basically a quiet day. Two o'clock's tablets again. We keep our medication here, but we've got to carry our dosettes along to the staff house and show them and they mark them off. And then er,.....we....well, at six o'clock we have another medication. And by ten o'clock it's our last medication, and we go to bed. .....It's a pretty boring day.*

Ian, interview 1.

However, where people are powerful,articulate and have long experience of the system, they may be able build this into a more acceptable routine and relationship.

DENNIS: *There are some marvellous things about it. I mean, tomorrow morning Irene's nurse –one of the nurses– will turn up, somebody that we KNOW....five minutes chat and Irene's injection...a part of the system that works beautifully. It's not a fuss at all, is it? It just happens. And it maintains a contact, and the nurse can see how Irene is and Irene can tell the nurse how she feels. Not only does that provide Irene with a weekly Depixcil injection it also is a regular, approved monitoring service, which is part of the re-assurance. I mean, Irene knows she's going to see the CPN every week, and it's nice because you get to know them. Have a chat.*

Irene and Dennis, interview 2. [although Dennis, as the carer, may view this differently from Irene.]

A few of the participants had begun to visualise a different kind of relationship between themselves and mental health professionals, but for most the image, if seen at all, was more a mirage than reality.

LINDA: *Well, you're meant to sit down with your care manager and say, instead of them telling you you're going to do this and do that, you can say I want to do this and I want to try that, and you try and get the funds to let you do that.*

ERIC: *Oh yeah! Can you see me doing that with my care manager?!*

LINDA: *Well there are lots of users that's got good care managers and they do get that information, and other users aren't.*

Linda and Eric, group interview 1.

The concerns raised in this chapter are all the more important because of the high cost to people of agreeing to accept mental health treatments that mark them out, to themselves and others, as a mental patient, given that those treatments cannot, even then, offer them a cure.

7.4 Discussion

Consideration of this material from the interviews again highlights a number of gaps and dilemmas that face service users, this time when seeking treatment for their mental health problems. Again these gaps become most visible when the priorities of service users are not those of the professionals who are there to offer them treatment [see also Chapter Six, on staff].

Their drug/ECT treatments cannot offer a cure in terms of a return to a normal, symptom-free life in the community without producing various side-effects that make such a normal life impossible to achieve. Nevertheless staff, driven by the imperative to assess and control risk, are in the main able to offer only these forms of treatment. Conversely, people with mental health problems can access help only from these professionals. Doing so may reduce their original symptoms only to replace them with different problems whilst refusing to address their wider social and practical concerns at all.

Accepting drug/ ECT treatments –and it is very hard to refuse them– has a number of implications. Firstly it places the individual within the medical/disease paradigm of mental illness, even though this may not be their own understanding of the situation.

Although such paradigms are not always clear cut and may overlap, blur and change, nevertheless the likelihood is that people are then seen as patients, whose understandings are secondary to those of the expert professionals who make the decisions about and provide their care. That care will be available mainly in clinical settings, with the understanding that prognosis is poor (Corrigan & Penn 1997). Mental health staff work to eradicate or control symptoms, to ensure that people continue to take their medication and to minimise risk. This in turn means that staff usually listen to patients only in order to diagnose and to assess risk. As Lindow says "This robs our words of their meaning" (Lindow 1996).

The people who took part in this study often had a very different conception of treatment and its aims. Firstly they wished to continue to see themselves as self-determining adults and aimed to continue to function in the community by developing ways of coping with symptoms with the aid of a range of biological and psychological treatments and social, practical and emotional supports.

Secondly, they were aware that taking the offered treatments would colours their relationship with significant others in their life –staff, family, friends– who would also see them within this medical/ disease paradigm. Individuals may wish to have an active and involved role in their own treatment but professionals' views of their condition may make this impossible. Rather people often find themselves in a relationship where they have very little power, choice or information or opportunities for dialogue and negotiation.

Thirdly, taking medication can come to command a central role in people's daily life. A significant part of their life may be structured around taking medication, making decisions about it, or coping with its side-effects. Consequently it comes to be a major topic of conversation for people, but one best discussed with other service users. This, in turn, helps to mark people out as inhabitants of "the mad world".

Fourthly, taking the treatments therefore, paradoxically, helps to ensure that people stay mad. They will have common experiences and feelings to share with other mentally ill people, who will be more tolerant and accepting of any visible side-effects. In conjunction with the other repercussions of becoming mentally ill –loss of job, income, house, family, friends– people increasingly find that they have more in common with people with mental illness than with the "normal" world, which becomes increasingly inaccessible to them. They therefore soon come to see themselves as permanently part of that world. Concurrently, as they find themselves thus exiled from the normal world, their best course of action may well be to stay as ill as possible in order to be eligible to access at least some practical help, emotional support and social contact, which the services target on those who are most ill.

Therefore it would seem that the interventions on offer in 1996 still, as Estroff reported in 1981, "cause physical harm, undermine self-esteem and disable people from returning to a valued position in society" (Estroff 1981).

The central dilemma of current mental health treatments is that, far from curing difference from the norm, they may rather emphasise it and ensure that people remain trapped in the world of mental illness. Since they then no longer have the option of leading "normal" lives, there are many perverse incentives within the mental health system to encourage them to act like a mad patient.

There are now signs that these gaps, and their important implications, are becoming more widely acknowledged.

> The key to delivering the treatment and support this group requires [people with severe mental illness who are hard to engage with services] is to understand the underlying incompatibility of what people in need want and what the services offer.....A consistent theme throughout the interviews was the feeling that services were dehumanising and controlling (The Sainsbury Centre for Mental Health 1998).

Even those driven by a desire for treatment compliance are coming to believe this might be more successfully achieved through a different style of service delivery.

> The personal relationship between patient and carer is of considerable importance in achieving and maintaining compliance....Another factor identified in research....is the level of patient involvement in decision-making....In a number of cases, patient dislike of depot injections was highlighted as a problem in achieving compliance (Howlett 1998).

An interest in access to other forms of treatment, especially talking therapies [psychotherapy, counselling], is a recurrent theme in user focused research (Rose et al. 1998) (Rogers et al. 1993). Underlying this may be, not so much a belief that these other treatments can effect a cure, as a desire for caring, social contact. Even if such contact can still be achieved only when accompanied by a treatment, at least people should have information about side-effects, the freedom to make informed choices about whether or not to take them, and should be delivered in an empowering and respectful way.

As Read has said:

> In my view, the crucial questions about mental health services are not to do with locations and technology but with understandings (Read & Reynolds 1996).

Just as service users and mental health professionals may employ different understandings of treatment, they may also hold different understandings as to what constitutes a successful outcome. Indeed there will be different understandings within these broad groupings too and service users may themselves be mental health professionals. Some people may be aiming for the ability to live in the community with major symptoms controlled, others may put more emphasis upon achieving a sense of self determination and empowerment. The extracts from the interviews have revealed the broad range of attitudes towards, as well as the common concerns about, their treatments that these particular people hold. Many value the relief of symptoms that medical treatments have offered and the sense of security that can come from placing yourself in expert hands. Many also worry about the costs of this relief in terms of unexpected side-effects and impact upon their wider, social life. Some are simply resigned to all of this, since they can see no alternative. Some are highly opposed to drug treatments and the world that accompanies them and feel that accepting them would mean losing a part of themselves. They may be unwilling to give up the few enjoyable parts of the experience of severe mental illness in exchange for a more mundane existence on medication. Gary, for example, spoke of enjoying the times when he felt very active,sociable, confident and full of energy during "manic" phases of his illness. He then described going into hospital to receive drug treatments which staff told him were making him better but which he perceived as returning him to a dull and hopeless existence.

Given the dilemmas and concerns discussed in this chapter, it is clear that service users face conflicting and contradictory messages about their treatment, just as they did about their relationships with staff, and the two sets of problems overlap and interact. In addition, as will be discussed in the

subsequent chapters of this thesis, they are further influenced by participants' considerations about other areas of their lives.

8. WORKS AND DAYS: SERVICE USERS AND DAILY LIFE

8.1 Introduction

" What are days for? Days are where we live.

Philip Larkin, "Days" 1964. "

This chapter is based upon material from the interviews in which the participants talked about their daily lives, both now and before their illness. All such material was initially stored under node 2.2., daily life. As the interviews progressed, a number of sub-nodes were added:

- 2.2.1. ward life;
- 2.2.2. boarding house life;
- 2.2.3. typical day;
- 2.2.3.1. benefits;
- 2.2.3.2. holidays;
- 2.2.3.3. housing;
- 2.2.3.4. neighbours;
- 2.2.3.6. carers;
- 2.2.3.7. advocates;
- 2.2.4. employment schemes;
- 2.2.5. day centres;
- 2.2.6. hostels.

Consideration of this material led to the decision to return to each series of interviews and both make notes on the main stories and events in each interview and series, and draw together material to construct each person's life story and to compare descriptions of important shared events, such as diagnosis or first hospital admission. [see Appendix for Ian's account] This provided a firmer context for consideration of not only this material but also that now contained in the two previous chapters.

In the light of these considerations, there were a number of possible ways to structure the material on a topic as amorphous as daily life. However I eventually decided to follow the scheme which most of the participants had themselves naturally adopted, which was to centre their discussions, as most people do, around paid work or the effects of the lack of it.

The service users who contributed to this study came from a variety of locations, backgrounds and social situations within the county. However, at the time when these interviews took place none of them was in full-time, or part-time, paid employment. This might seem to be a consequence of the study's recruitment strategy, but many research studies and surveys, including the large-scale Psychiatric Morbidity Surveys, have shown that people with severe mental illnesses are very much more likely to be unemployed than people without (Meltzer, Gill, Petticrew & Hinds 1995). There is no easy or clear way to categorise the participants' past, or current, employment status, but the following list will give some indication of their situations and backgrounds [a more detailed account is contained in section 5.2. of chapter 5.];

- Lenny, Matthew, George, Mike, Paul and Mabel attended an NHS run sheltered employment, packaging workshop, for between 3 and 5 days per week. Apart from Matthew, they had been long-stay patients at the hospital but were now resettled in the community. Before the re-settlement process, they had worked on the hospital site [farm, factory, domestic work]. Lenny, Mike and Paul had been in full-time work before their mental health problems began.

- Mark and Harry were both retired. One had previously worked as a lecturer, the other as a labourer. Harry's wife had died many years ago. He now lives alone and attends an NHS run mental health drop-in centre one day per week. Mark is married and lives in his own, large house.

- Darren and Ian [both young men] were hospital in-patients and had been living mainly on the hospital site for a number of years. Neither worked at the time of the interviews, although both had tried a variety

of labouring, farming and factory jobs and training schemes in the past. None of these had lasted for more than a year or two. A range of activities and classes were now available to them on the site, for example use of the gym, art classes, computer classes. Both did make use of them intermittently.

- Carole, Jane, Linda and Irene were married and/ or had young children. They spent much of their days looking after the house and children.

- Barry, Mary, Eric, Gary, John and Tim attended the same day centre, for up to 3 days per week each. All had worked full-time before their mental health problems began, in factories, as labourers or in the Royal Navy.

- Joseph lived alone in the community. He had been in and out of hospital over a number of years and had spent several years living and working within a monastery.

This chapter will follow the same structure as the two previous ones inasmuch as it begins, in section 2, by describing participants' accounts of an ideal typical day, which would include having a "proper job". Section 3 focuses on their accounts of actual typical days, which offer only sheltered employment or an unstructured life on state benefits, neither of which fit their hopes and criteria for a valued and meaningful day. Section 4 concludes the chapter by discussing the difficult decisions that service users once again face in trying to maintain their daily lives, and the ways in which these judgments and decisions impact upon their relationships with staff, their decisions about treatments and their wider social life and self image.

8.2 The ideal day

As was stated in the Mental Health Foundation's 1994 report "Creating Community Care for people with Severe Mental Illness":

> Having a mental illness, even a severe one, does not suddenly change the basic human search for a full and fulfilling life. Nor does it alter the fundamental requirements on which such a search is necessarily grounded - an appropriate place to live, an adequate income, a meaningful social life, employment or other satisfactory day activity, and help and support when needed (Mental Health Foundation 1994).

When the people participating in this study spoke about their daily lives, despite their varied backgrounds and situations, there was a general desire to be able/ allowed to work in a "proper" job. Seventeen of the twenty-one people who were interviewed expressed the belief that this would greatly improve the quality of their lives and their sense of self-worth. The four people whose interviews did not include statements of this kind were Mark and Harry, who had managed to juggle their bouts of illness with holding down a job and were now retired, and Darren and George who each gave only one interview and the topic did not arise. No-one said they would prefer not to have paid work, but, equally, no-one thought it a realistic hope. These findings correspond with those from other, recent research (Rogers et al. 1993) (Barham & Hayward 1991) (Perkins, Buckfield & Choy 1997).

Four main themes emerged from the interviews outlining what people wanted from a job:

8.2.1 Interesting work

The definition of interesting work varied from one person to another, but many would have been happy to have their pre-illness jobs back.

MARY: *As well as the money side and that, you've got to have your health, both mentally and physically. Otherwise I would go back to Joes tomorrow: That's the factory where I worked.*

BARRY: *You would?*

MARY: *I would, definitely. I'd love to.*

TIM: *Yes, I would, if I could; go back to work.*

MARY: *If I could go back to work and do five days a week, and overtime, the way I used to, I would be back there tomorrow.*

TIM: *Yes, I would as well.*

Mary, Barry and Tim, group interview 7.

ME: *What are your hopes for the future?*

IAN: *To live in a house with Laura and her daughter and get a job. A proper job and be well.*

ME: *Have you got any ideas about a job?*

IAN: *Not really...although I would like to go to college and do sociology. But I'm not really intelligent enough for that. But I am trying to read some books about it. I've got two massive great books upstairs. I got them off the staff. They look really interesting.*

Ian, interview 1.

BARRY: *What job would you like to be doing, John, if you were well enough?*

JOHN: *Me technician's job.*

BARRY: *You would like that back?*

JOHN: *Why yes. But I couldn't cope with it now, like. I'm beginning to forget all my training and whatnot.*

BARRY: *But you haven't changed your.....*

JOHN: *I haven't changed my attitude and what I would like to do.*

Barry and John, group interview 7.

8.2.2 A living wage

Again people's idea of what constituted a living wage varied, but their expectations were certainly not excessive and were mainly in line with their pre-illness earnings.

ME: *Mary, what did you like about working at Joes?*

MARY: *The money. There were three shifts –six in the morning til two in the afternoon, two in the afternoon til ten at night, and ten at night til six in the morning. And they worked you seven days if there was a big order on, and that was, like, your bonus money. If you were prepared to work hard, you got your bonus. You'd be working your guts out. But I would, definitely. If I had my health, I would go back to work.*

Mary, group interview 7.

IAN: *But being in the hospital factory...I didn't like that. I didn't like some of the lads up there, because there were some big mouths who were always causing trouble for other people. And the money was terrible like! Sixteen pounds a week! It was useless. You can't do much on that! And that was for every day, five days a week, for sixteen pounds!*

Ian, interview 2.

8.2.3 Tolerance of mental health problems/ an supportive environment

People realised from their past experiences of trying to maintain themselves in open, paid employment, that this was a vital element for success.

ERIC: *You CAN'T think about a job, because as soon as you try to even think about it, to get yourself to that stage, it's freak out time, you know, even though you might desperately want a job. There's nothing better I would like than to work, but I know I can't. Who is going to hire someone who might be there two or three weeks and then they go through a bad spell and so they're off, when you think there's nothing discernible wrong with them. They haven't got a broken arm or a bad back or anything like that. They can be seen walking around the streets. So what happens? You're called in to personnel, you know? There's no leeway, and all that preys on your mind too.*

Eric, group interview 1.

TIM: *Well there, you see, the thing about the sheltered workshops is, they've got clinical staff. So I'm not threatened there. I know if I get down, I can go upstairs and get support from them.*

MARY: *So you don't get the pressure like if you were in a factory outside?*

TIM: *No. It's just, like, the normal pressure that you feel anyway, and, if I get it, I can go up and talk to them and that makes us feel safer. But I couldn't go if that wasn't there,*

BARRY: *So you couldn't work five days a week in a factory or something?*

TIM: *No, I couldn't. The pressure would be too much.*

JOHN: *It should be planned for directors of companies to train all of their first-aid nurses and that to take on the role of mental nurse, or something like that. A dual role for those nurses. Then we could go back to work.*

BARRY: *There are some places where they're good. I've heard of some places where you get a lot of support. But usually it's, if you're off like three days after a month or so at work, and then you were off two days the next month, they would say, "Well, Tim, I think we'll have to watch you from now on. You've only been here a month and already you've been off for a week." You know what they're like. And that would start to get you worried. It was that way for me anyway. A lot of pressure.*

Tim, John, Barry and Mary, group interview 6.

8.2.4 A work situation that enhances self esteem

As in chapters six and seven, this reflects the importance of supporting people in maintaining a positive self-image and sense of self esteem. Just as the treatments on offer may be medically effective but nevertheless lose much of their therapeutic power and appeal if delivered in an disempowering and disaffecting way, so too with employment opportunities.

GARY: *And the thing is, it would be degrading for me to go to that sheltered employment because all you're doing is, like, putting a couple of bars of chocolate in a box, or something like that, and then closing the box lid and passing it on to someone else.*

ERIC: *So, if you're depressive when you start something like that, when you start off in the morning, then you're ready for a visit to the acute ward by the time the night comes round [laughter]. I couldn't do it. It would freak me out straight away.*

LINDA: *I mean, if that's meant to be stimulating your head!! Well, I would hate to see something different! [yeah, yeah, giggles]*

Gary, Eric and Linda, group interview 1

MARY: *But if you could get better, or you were better, and you were outside, and you had a job....in five years time, why you would think you were the bloody king of Newcastle, wouldn't he, Barry?*

Mary, Group interview 6.

BARRY: *I feel like I'm never going to be part of the community again. Not like I used to be, like I was. When I had a job, I felt like I had a bit of self-respect. But now I feel as though I'm just..... and this is how I'll be for the rest of my life really. Just coming here..... And I see people around us who have deteriorated alarmingly, and I'm frightened of becoming like that.*

ME: *What job would you like to be doing, Barry?*

BARRY: *Me?....I would like to be studying, history, and doing a degree and research, and things like that. But that's just.....an impossible dream really. The jobs I have had, they were labouring and things like that.....Like we were saying before, if you've got a job, you've got self-respect, and things like that.*

Barry, group interview 6.

8.3 Actual days and employment opportunities

What most of these people would like to spend their days doing, [interesting work for a living wage, in a setting that supports people through difficult times and enhances their self esteem], is not actually "an impossible dream". It is possible to provide the sort of jobs they are asking for, but, at the moment, we, as a society, are choosing not to do so. None of them could find a job which would provide the four things they were asking of it. For some of the women this was slightly less of a problem as they could been seen as working by running a home and looking after children. Indeed the argument of this thesis is not that people with mental health needs should all be sent out into paid employment. The private, caring work undertaken by women, or men, is, or should be, equally valued and able to fulfil the criteria which the participants set for a meaningful day in the "ordinary life" seen as one of the goals of the new community care. The two men who had managed to keep on working in some fashion both suffered from bi-polar disorder. Recent research has shown that these are the people most likely, if any, to be able to carry on working (Hill, Hardy & Shepherd 1996) (Rogers et al. 1993).

However, instead of "real" jobs the people involved in this study had found themselves facing a very limited choice of daytime activity –a life on benefits plus a sheltered employment scheme, or a life on benefits without an employment scheme.

The interview transcripts give some insight into the kinds of considerations that influenced people's decisions regarding these, very limited, options now available to them.

8.3.1 Sheltered employment schemes

The schemes on offer to the people involved in this study met only one of their four criteria, that is they were tolerant of their mental health problems/ not stressful. This is, however, a very important criterion, since it is the one that outside, open, employment is not willing to meet. Whilst it is possible to envisage more creative and humane sheltered employment schemes, such as some of the schemes now beginning to operate in other parts of the country (Nehring & Hill 1995) and abroad, the ones that these people had experience of generally failed miserably to meet their other three criteria

Firstly, they did not involve interesting work. During the time of the interviews the work at the scheme was either emptying bottles of mineral water which had passed their sell-by date, preparing conference identity badge holders, painting the "lollipop" sticks for crossing patrols, washing off labels from bottles of bubble bath, or, sometimes, nothing at all.

ME: *Actually, we were talking about the employment scheme before you came in. We weren't really sure what it's meant to be for.*

TIM: *Nor are we! [laughter] It's supposed to be therapeutic. But I've just been today, and for therapeutic.....! I tell you, I've come back thoroughly depressed. There's no work there at the moment. It's just putting elastic bands on cardboard pieces. Five elastic bands! Just doing that all day! Not much stimulus to the mind in that, is there really?*

ME: *It doesn't sound very therapeutic, no. What other sort of jobs do they do?*

TIM: *There have been other jobs in more interesting than that. There used to be a lot of work for John Grahams, which was a crop spraying.....we used to assemble different parts and that. But somehow they've gone by the board, and there just doesn't seem to be the work there lately. There was some working with nappies, but they wanted too fast a production. They couldn't manage, you know. And so that was stressful too.*

Tim, group interview 5.

LENNY: *Well, it's not so bad. Not so bad now. I'm glad we've got a bit work in again. We've been idle for a few days like. It's a long time then. It's hard to put the time in. But we've got the badges back now. It's the same job, but er,.....I've had that job for years now.I must be one of the longest ones here like, and I've kept that job going on for them for a long time now.*

Lenny, interview 2.

PAUL: *You see, in this factory we're bored. We could do more difficult work, if they could get it in. But that's not happening though, In fact, it's falling back. They just don't tell you what's happening. They don't tell you anything, what's going on. There's less work than there should be, and less people.*

Paul, interview 1.

Secondly, they fail to pay a living wage.

LINDA: *Or you can always go and work at the employment scheme.....for fifteen pounds a week. [laughter] Slave labour!*

GARY: *That's another thing.....the more you get into these services..... Like, you can start off going to the pop-ins, and then you come here [to a day centre] and then the next thing you know, you're at the employment scheme, and, I mean, it's.....well, I've got really strong feelings about it. It's diabolical!*

LINDA: *It's just sick! You're doing the same amount of hours as anybody else at another factory and you're getting paid nought for doing all that work. And you're only getting paid that money because you're on benefits. You're only allowed to get paid fifteen pounds a week because of your benefits.*

Linda and Gary, group interview 1.

MARY: *But if you're.....like at Tim's employment scheme, what is it you get?*

TIM: *Three pounds a day.*

MARY: *Three pounds a day!! Well, that's bloody disgusting, that is. So, in fact, if you go five days a week, that's fifteen pounds!! They're all on*

more than that an hour. But if you're a mental health user, you're on therapeutic wage. Three pounds a day!

BARRY: *It's hard to build up your self respect like that.*

TIM: *uh-huh.*

MARY: *It gets me on my soap box, it does. It makes my blood boil!*

BARRY: *When you think of all they're contributing, through all the time they're putting in there. They should get their share of it, through what they've put in. Now, three pounds an day is just like what you're saying. It's disgusting. That's no incentive. You'd have to be really keen on it to do it for that.*

Mary, Tim and Barry, group interview 6.

IAN: *And then they got us some work. They started us at the sheltered employment, the woodwork site.*

ME: *And what did you think to that?*

IAN: *Didn't like it.*

ME: *Why was that?*

IAN: *Because of the wage. Terrible wage. Three pounds a day! It's terrible that. It should be about forty pounds a week. That would be enough for me.*

ME: *That would make you feel better about it?*

IAN: *Oh yes, it would. I wouldn't mind going back to work then.*

Ian, interview 1.

MIKE: *[in the old hospital] I had to work every day, like as if I was at work, as if I was doing a job. And a five day week and all! Three pounds, six a week, I got. And a quarter to fill at the shed, and it was a canny size too, to fill every month with woodwork. And it had to be good. Things we made entirely ourselves. If it had been called a workplace, they would all be charged with giving us the wrong money. But that was the racket, you see! That's why they call it occupational therapy! [hollow laugh]*

Mike, interview 2.

Thirdly, they do not enhance people's self-esteem.

BARRY: *You see, I wouldn't mind doing something that I quite liked, if I was getting extra money.....like about forty-five pounds a week. I would like the cash incentive and I would try for that. But, like Mary and the other people have said, if you get three pounds a day, it degrades you.....you feel....do you know what I mean?. You don't want a lot of money for doing it, but you would feel a lot more.....and if it was made comfortable for you with the doctors and that. You could feel more secure. You know, get into liking it, if it was done like that instead.*

Barry, group interview 6.

Nevertheless, some people did choose this option. Their main reason was not a positive choice, but a feeling that it was better than the only other alternative, of a life on benefits without such a scheme, inasmuch as it did at least give some structure and purpose to the day.

TIM: *But then, all people are different. My illness is accelerated by having no structure. If I have no structure to my day, I completely go under. That's the trigger for me. But I appreciate that some people cannot even be motivated to start, which must be much worse. But to me, I've got to be doing something, or I completely..... So that's why the work at the employment scheme can sometimes be a little bit.....repetitious. But, of course, I do the User Voice, and I enjoy that better. But the fact that I'm in a structured environment helps. And that's the reason why I do it. So it has a therapeutic value, you see,.... for me. But not for everyone.*

Tim, group interview 6.

BARRY: *But when you don't do that [employment scheme], there isn't the structure in your life, you see. You feel useless. You feel as though you're not contributing to the community. There's a lot of intelligent people who have mental problems and they would like to do some interesting things. I know I would. But I find it difficult, you know? And there's not the resources here to do something constructive, is there?*

Barry, group interview 2.

MATTHEW: *And once the sheltered workshop opened, I got a job there, and it helped us a lot like. Kept me mind occupied, working. First, we had to do the place out. Paint it, and decorate it, and that. Because it had been a hospital, a day hospital. They always give you something to do like, something to occupy your mind.*

ME: *So do you like it here?*

MATTHEW: *.....er, yes. It's alright like. [hesitant, rather than wholehearted] I like it here. It passes the time away. It's better than sitting in the house watching the tele all the time.*

Matthew, interview 1.

ME: *Do you think you'll stay working here now? [sheltered workshop]*

MIKE: *As long as I can. Yes. It's a daily practice. It keeps you regular. If you're just lying about in the house, there's all the turning over different things, you know. And you're just depending on the house. I like to see the different faces. That's what life is these days, isn't it? Regular work. daily work.*

Mike, interview 1.

In addition, the employment scheme provided a physical place to be and access to different people.

BARRY: *[Having a job] would fill the time in as well, wouldn't it? You would feel part of society again, and a little bit..... do you understand?..... Because I've read books where people like Bertrand Russell and that were saying that everybody, and it doesn't matter what their job is, it always does them some sort of good in a way to have a job..... You know, because it makes the time that they've got more valuable, the holidays more enjoyable. He sort of said that, if you didn't work, you sort of.... the boredom sets in, and.....that's it.*

Barry, group interview 8.

MATTHEW: *At least here [sheltered workshop] you've got people around you like. It's not like you're just stuck out on your own. because, if you've no job, and people are unkind, that's when the depression sets in.*

Matthew, interview 2.

IAN: *I didn't like it much [employment scheme]. The best bit was being on the wagon, on the truck, delivering. Doing the deliveries, that was the best part, because you could get about the North East all the time and see different places and that.... And some houses you would go to, you would get a tip, maybe some cigarettes each, or a bottle of Brown Ale, or something. That was the best part.*

Ian, interview 2.

Some people were pleased to have even the little extra money that the schemes provided.

MATTHEW: *I don't drink so much now, mind. And I only pay three pounds for my baccy and that lasts me the week. I only smoke baccy, because it's not so expensive. So I'm pleased to get that money from coming here, you see. [sheltered workshop]*

Matthew, interview 3.

MIKE: *Well, I work here [sheltered workshop]. It's good on Mondays. This is a Monday, isn't it? It's like a short day on Monday. It feels as though it's a short day on Mondays. But on the Tuesday..... you look at the clock constantly. Oh God, it's so slow! But, when it gets to Wednesday, that's my incentive day, because I get my pocket money on a Wednesday night. Keeps us going, you know? And on Thursday, we get our pay here. That's good.*

Mike, interview 1.

For some people, therefore, the employment scheme had enough therapeutic value, because its structure accepted and supported their mental health problems and gave them a sense of their place and worth in the world, that they were willing to spend their days there.

However, the people who attended it were mostly men and most were viewing it as an option in the context of having spent many years as long-stay patients. Indeed, this was an area where, as with access to staff, it could be argued that those who had been in the hospital were, and are, better served than those people who have largely managed in community settings. Mabel, Lenny, Mike and Paul had all had to work on the hospital site and continued in the sheltered employment scheme. Other people, who had not had a long in-patient stay, generally did not have anything like this continuous work history, and viewed the available employment schemes as not suiting their needs; not for women, not for women with children, not for young people, not for people with less severe problems [they thought of the long stay patients as different from them.]

8.3.2 A life on benefits

Therefore many people in this study, basing their decision on their particular background and situation, found themselves, as a consequence of their mental health problems, facing a lifetime on benefits. This, in effect, means a lifetime of empty days, because these benefits are given only to those who can demonstrate themselves to be unable to work. Brandon has described being left to pursue this type of life as "the everyday trauma of eventlessness" (Brandon & Brandon 1995). Therefore people once again found themselves facing the dilemma that the most therapeutic choice available to them –a life on benefits–, ran contrary to what they most wanted to improve their "health and social functioning" –a job (Hannigan et al. 1997). The 1994 Mental Health Foundation report also highlighted the importance of this:

> Meaningful occupation is consistently rated by users and carers as one of the most important elements in an effective community mental health service (Mental Health Foundation 1994).

This lack of meaningful daytime activity was experienced by people whatever their situation –whether at home, attending a day centre or in hospital.

> CAROLE: *What do I do? Well, I just sit at home. I do all my work. I do two lines of washing, and, after I've done everything, I might gan for a little walk sometimes.*
>
> Carole, interview 1.

> ME: *So what can you do during the day?*
>
> GARY: *Well, I come here [day centre] every day. This in itself is a good place for community care. I come here every day nearly. Three and a half days a week I'm allowed. And outside that time I've got some phone numbers I can ring if I need to contact someone. But this is like a rarity, man. It is a good place like, you know.*
>
> ERIC: *Yeah. It's usually a back room somewhere that's in use for an hour or two a week and that's it.*
>
> LINDA: *Yeah. I get the majority help off here, not off my care manager.*
>
> ERIC: *I see nobody. It's just people coming in here and talking to other people. That's it.*
>
> GARY: *Shocking. It is. It's shocking.*
>
> Gary, Eric, Linda, group interview 1.

Even people who are now in-patients [the new long stay] no longer have to work on the site. Their days are structured only by regular checks that they are complying with their medication regime, as this extract from an interview with Ian again shows.

> ME: *What's a typical day like here?*

IAN: *It's er,..... very quiet. er,..... A typical day's like.....well, getting up early. Sometimes I get up really early, at six. And I'm up in the middle of the night sometimes, and I come down for a smoke and just to check the house and make sure that my hi-fi hasn't been pinched. And, er,... like today, I was up at eight today. I got up and then went back to bed and slept until half-past eleven. Laura was up. Then we would have our morning medication at the staff house and come back here. And then we would sit and watch the tele, or maybe go to the gym, or have the radio on, or have friends around. And er,.....it's basically a quiet day. Two o'clock's tablets again. We, er,.....At six o'clock we have another medication, and we go to bed. Er,.....it's a pretty boring day. If you're not used to the hospital, you might say, "Oh, it's right boring here. It's quiet, and it's um,...." It's a different..... What I'm trying to say is, I've been well and I've been unwell. And my life before I come to this hospital was quite a normal life. But, like, it does take getting used to, living up here. But, once you are used to it, it's quite nice. It's a different way of life to your life though.*

Ian, interview 1.

Ian, however, has access on the hospital site to many of the things that others in the sample would like, for example constant access to known staff members, leisure facilities, a sexual relationship, but which have not been [re-]provided as part of community care.

Most people spent their days listening to music on the radio, watching television, drinking tea, smoking roll-ups and walking the streets. Most people's social networks now consisted of mental health professionals, other people with similar mental health problems and family members. Only Irene, Jane and Mark made mention of any "outside" hobby, interest or friend.

Mark and Irene, both free from financial worries and in long term relationships, were aware of the importance of these in shaping their experiences.

DENNIS: *I honestly don't know what happens to other people. If there was another person with exactly the same symptoms and exactly the same illness as Irene has, and that person was living in digs on his or her own, a room.....I don't think they'd survive. They'd be.... There'd almost be a need for hospitalisation on a permanent basis, because that's the only place you'd find the comfort or, if you like, the security, of a home base.*

IRENE: *They do go out into rooms, and to live on their own, and, as Dennis said, I don't know how they manage. They must have an inner strength to help them through, I should think, or they just collapse.*

DENNIS: *I think this is the key thing with this sort of illness.....As Irene said, it's always there. And, if you've got a good base, and good local support, then ninety percent of the time you can cope. but it's going to be so much harder for any patient*

IRENE: *without that base....*

DENNIS: *without that base. I mean, we're very lucky, we've got a good base. We've got a lovely house, enough money, we're both here and, um,... we have good nursing staff.*

Irene and Dennis, interview 2.

8.4 Discussion

This section of the study again highlights the many gaps between the service users' own perceptions of their needs and what would help them to lead a fulfilling life, and what is currently provided. Once again the spaces provided for mental illness do not fit service users' own templates and provide them with contradictory messages about themselves and their place in society.

The value and importance of work to our sense of self and of our place in the world and to our mental well being is well documented and generally acknowledged:

> Work tells us who we are and enables us to tell others who we are (Perkins et al. 1997).

However the importance of employment as part of the care and treatment of people with mental health problems has, arguably, been one of the casualties of the move from the old institutions to community based care. Work was an integral part of the asylums established in the 1800s and continued to be so. Occupational and industrial therapy, with the aim of enabling people to return to open employment, were endorsed as important elements of mental health service provision throughout the early 1900s also. However the rising levels of unemployment since the 1970s have provided an economic and social landscape that militates against the achievement of this aim and employment has gradually disappeared from recent mental health policy documents, the implication being that it now lies outside the remit of those services and is no longer a high priority. As Schneider has pointed out:

> Lacking a policy lead, the potential benefits of employment also remain largely hypothetical, since the provision of work opportunities in contemporary community mental health care in the UK

> remains inconsistent, unco-ordinated and unevaluated (Schneider 1998).

Any illnesses, but perhaps particularly chronic ones, are experienced and described both differently for each individual situated within his/her own context of race, class, gender and age and in the same way, inasmuch as we all are subject to the same prevailing and dominant ideologies and belief systems (Radley 1993). The service users spoke to me and considered their options in this light, that is within our current local understanding of what "normal" people are, do and have. Hence they wanted to have a job, not only for its own sake but as an entree to the normal world; not only to fill their days more pleasantly than they could without one, but also because it would allow their evenings, weekends and holidays to be likewise filled, with friends, hobbies, activities and relationships –fun. It would place them within the same space-time constraints as most other people in society (Estroff 1981), rather than having their days structured only around medication and the arrival of mental health professionals, interspersed with large amounts of free time in what is for other people an all too busy world. They recognised that gaining an income was but one of the benefits of being in work. One of the major themes to emerge from this study is the crucial importance that these service users attach to having meaning and value to their lives, a reason to carry on. The opportunity to be in employed in a work setting structured to support their needs could go a long way towards countering the many areas of loss they otherwise often experience with the onset of their mental health problems, such as the loss of their family, friends, spouse, home, which contribute to their sense that they no longer belong in, or contribute to, society and their local communities.

As the study of work, empowerment and community undertaken by Nehring, Hill and Poole concluded:

> "Being part of the community" involves enabling people with long term mental health problems to develop and maintain individual interests and relationships and to occupy purposeful roles which are valued by the community and themselves (Nehring, Hill & Poole 1993).

However, having such a purposeful and valued role, whether through paid or other work, was no longer an option for the participants in this study. This is a finding which resonates with and adds to that of other research with people with severe and enduring mental health problems:

> If you want to work, and are able to work, the main effect of a mental illness diagnosis will be to stop you getting the work

you want. Sooner or later, you must face up to concealing or reformulating your past (Campbell 1997).

Gaining, or, perhaps more accurately, retaining, employment is one of the greatest problems facing those with mental health problems (McCrum, Burnside & Duffy 1997).

This is a nation-wide problem, as revealed in the 1995 Psychiatric Morbidity Survey, which showed 39 percent of people with psychiatric disorders in employment as compared with 71 percent of people without (Meltzer et al. 1995).

Despite the high value that service users put on employment, helping them to procure it has been, and remains, a very low priority. Instead the political/ social/ economic decision not to make jobs available to them has been recast as their individual psychiatric symptom, an inability to work. In our society this exclusion from work generally leaves people without a valued social role. In this study the only people who managed to overcome this dilemma at all were those like Jane, Mark, Irene or Carole, who had other roles still available to them, for example as wife, mother or husband. These were not always without attendant problems of their own, but they did give these people a greater sense of self-worth. For those, the majority, without these other roles, the lack of employment opportunities was yet another obstacle to their recovery of a sense of self worth and integration into their local communities. As Barham found, in his study of people with schizophrenia living in the community:

> To be without a valued social role is to be made to feel worthless....our participants were persistently haunted by doubts about their worth (Barham & Hayward 1991).

Thus excluded from work people had to find some other source of secure income, which could only be social security benefits such as Income Support, Disability Living Allowance and Incapacity Benefit. In order to qualify for these people have increasingly to be, and stay, as ill as possible. The current system offered nothing to support people through a transition from being ill to being well enough to manage unsupported. Instead people with severe mental health problems, who most need the advantages that employment brings in our society, are both excluded from it and forced to rely instead on an inflexible benefit system that contains within it perverse incentives to be seen to be ill.

ERIC: *I had to go to the job centre the other week to get some application forms. It took me three attempts just to make myself go there. People have got no conception of how difficult it is, even the simplest of things.*

LINDA: *And I'm terrified in case they take me off the sick.*

ERIC: *Well, I know they'll not do that to me.*

LINDA: *I am. I'm terrified they'll take me off the sick.*

Linda and Eric, group interview 1.

JOHN: *It's a very difficult situation you're in like. When people say they're well enough to do a job, they're only allowed to earn a certain amount of money, because of the benefits. So you could be on a lesser rate per day like, for being better! So, you're looking at yourself and saying, "Well, should I do it, or should I not? How much am I going to say I'm able to do?" It's all money like.*

John, group interview 1.

ME: *Has having this illness had much effect on your life?*

MATTHEW: *No, it hasn't affected my life. It's just I can't get a job like, with being on the sick. Anyway, there's not much work anyway, is there? [laughter] I'm probably better off being on the sick.*

Matthew, interview 3.

BARRY: *It's the old story. It's getting better. It's getting better on one hand, and losing benefits through getting better. So you're frightened to get better. And that puts a strain on you.*

Barry, group interview 3.

Much recent research, across a variety of disciplines, now argues in support of a concept of the self best understood not as an empirical and transhistorical entity, but as a narrative, and therefore inextricable from its location in history and culture, inasmuch as we make ourselves by telling stories about ourselves from our cultural menu of available narratives. In the light of this, the importance of people's daytime activities lies not only in those activities per se but also in their substance in the stories we can tell about ourselves and thus in the people we, and others, can see us as being. By providing only such limited daytime options for people with severe mental illness we reinforce the dominant cultural story about them, –a tale of negative difference, of lack and disability–, rather than providing the stuff of other, positive

tales (Fullagar & Owler 1998) (Greenberg 1995) (Reissman 1991). It is in these ways, rather than through standardised quality of life tools and scales that the real success, or otherwise, of community care for people with severe mental illness should be judged, for the danger of such tools is that they continue to focus on individuals, rather than society and structural discrimination.

Although the official policies and debates around community care for people with mental health problems are about providing a better system of care and helping people to retain a valued role (Department of Health 1989) (Department of Health 1993*b*) (Northumberland Health and Northumberland Social Services 1996), its realities, as experienced by current service users, are still as much as ever about deskilling and disempowering people through structural discrimination and keeping them firmly within the "mad" world.

9. LOST IN SPACE; SERVICE USERS' VIEWS ON THEMSELVES AND OTHERS

9.1 I Am

This chapter begins with a poem written by John Clare.

> I am: yet what I am none cares or knows,
> My friends forsake me like a memory lost;
> I am the self-consumer of my woes,
> They rise and vanish in oblivious host,
> Like shades in love, and death's oblivion lost;
> And yet I am, and live with shadows tost
> Into the nothingness of scorn and noise,
> Into the living sea of waking dreams,
> Where there is neither sense of life nor joys,
> But the vast shipwreck of my life's esteems;
> And een the dearest -that I loved the best-
> Are strange, nay stranger than the rest.

John Clare was born in Northamptonshire in 1793. Like his father, he worked as a farm labourer. In the 1820s he published a number of volumes of poetry, which were all well received. However, in 1837 he was admitted to High Beach Lunatic Asylum in Epping and, apart from a brief escape in 1841, he spent the rest of his life in an asylum, dying in 1864.

Despite the plethora of mental health legislation and guidance issued in the intervening 150 years since John Clare wrote "I Am", his feelings and experience are still echoed in the interviews conducted for this study.

This chapter is based upon extracts from the interviews in which the participants were talking about their views on themselves and others. This material was initially coded and stored under node 2.1.3., self and others. As the interviews progressed, a number of sub nodes developed:

- 2.3.1. family;
- 2.3.1.2. family involvement;
- 2.3.2. friends;
- 2.3.3. self;
- 2.3.3.1. illness and life;
- 2.3.3.2. making it crazy;
- 2.3.3.3. resolving differences;
- 2.3.4. the public;
- 2.3.4.1. normal life.

This material was read in conjunction with the notes on life histories and stories. From this it was again clear that the participants were faced with a gap between their pre and post illness selves. Sections 2 and 3 of this chapter discuss the ways in which the participants came to hold these views of themselves, through their relationships with family, friends, professional staff and the wider public. Section 4 concludes the chapter by discussing the importance of social networks and the ways in which they are structured by the current response to mental illness, which thus leaves people with mental health problems as still "The Other", whatever the rhetoric about inclusion and community integration.

9.2 The ideal me

The ideal me that emerged from the interviews is an ordinary, well person, often the individual's pre-illness persona.

ME: *How would you have liked your life to be?*

IAN: *I would probably be married by now....I might have been married and had a good job and that. I would have liked to have been an electrician...or I would like to run a nightclub, cos I used to live in a club with my parents, and I know about cellars and that, and beer. So that's what I would like to do then, Marilyn. I would like to have a family, and a car, and a job. Just ordinary things.*

Ian, interview 4.

MIKE: *Before all this happened, I worked hard at the shipyards, and I did my apprenticeship there, and I developed into a draughtsman, apprentice draughtsman. And all my ambition then.....I don't want to be a great big boss or anything, being a leading draughtsman is a great accomplishment. Being a leading draughtsman in our place, that was all I wanted. Aye.*

Mike, interview 1.

9.3 Actual selves

To read through the informants' descriptions of their current selves is a distressing and shocking experience. Unlike other [physical] illness accounts, these people could find almost nothing positive to say about the way in which their lives and self-image had been changed by the experience of psychiatric illness.

The words and phrases that people most commonly used to describe themselves were:

> damaged, not whole, worthless, wicked, punished, eccentric, odd, watched, crazy, devastated, weakened, destroyed, alienated, excluded, feared, frightened, a pest, rubbish, dragged down, a burden to others, different, frustrated, outcast, incurable, knocked back, trapped, not right, struggling, a lesser being, marked out for ever.

Barry's feelings were echoed by many others:

BARRY: *One of the main things about mental health problems is that you feel bad about yourself, like you're a worthless person, that you're a wicked person and you're being punished in some way. And that it's your fault.*

Barry, interview 1.

9.3.1 Searching for the self

How and why did all these people come to think of themselves in this way; as damaged beyond any hope of repair; as someone that other people constantly watch and are frightened of? What are the implications of holding this view of yourself and your situation?

To find myself faced with these questions and believing them to be important to my thesis posed problems for me, as a researcher. This was not what I had expected to be writing about: My original concern had been with my informants' views on the health and social services with which they had contact and the policy changes they had experienced. Yet, as the interviews progressed, it became clear that their responses to these aspects of their lives could not be understood in isolation from their views and experiences in other important areas of their lives. Re-reading the interview transcripts, I was struck over and again by people's expressions of feeling lost and confused in the economic, moral and social worlds in which they now found themselves. Consequently I had to acknowledge my own limitations and recognise that social researchers can also reflect and reproduce the very weaknesses and problems that service users highlight, since the funding for research is often divided into categories that parallel the boundaries and limited responses that service users find so frustrating.

The ways in which we come to have an idea of our selves and the influences that inform our view are still disputed areas. The approach which Fay (Fay 1996) calls "atomism" is rooted in the work of the Rationalist philosophers of the Renaissance period and claims that each human being is a separate and self-contained entity whose abilities, needs and beliefs arise from within that particular entity, rather than as a result of its social interactions, i.e. it views the self as a monad. More recently however competing approaches [Hegel, Satre, Nozick, Parfitt] have argued that the self is not one, fixed entity but rather arises from the interaction of many, fluid selves formed during contact with other people, i.e. that the self is inherently social. Pursuing this line breaks through the dichotomy of thinking about oneself and society as separate, replacing it with a self that is continually constructing itself within the boundaries of the narratives given to it by the other people with whom it interacts. Therefore the tone and nature of the responses to themselves that people with severe and enduring mental health problems receive are of vital importance in their construction of their selves.

What are these responses like?

9.3.2 Family relationships

> And een the dearest -that I loved the best- Are strange, nay stranger than the rest.

For people with severe and enduring mental health problems, as for all others, family relationships play a crucial role in decisions about the nature and place of one's self. In the interviews for this study, people spoke of family

relationships which were often tense and of their ambivalent feelings about family members. Whilst there may be nothing unusual in that, it was apparent that the onset of their mental health problems had placed additional strains on these relationships. Nevertheless, all those interviewed still maintained some links with their immediate family and valued the practical and emotional support that this provided.

GARY: *Even when I did get a referral to see a psychiatrist I had to wait for another three weeks, and I was virtually.....well, I was lucky I was living with my parents, you know because I was housebound really, and, if I'd been living on my own, I wouldn't have been eating, or going to the shops, or doing anything really, because I was just.....er,...terror-stricken basically.*

Gary, group interview 2

Ian talked of the help his parents still gave to him, both through giving him extra money for new clothes and toiletries and by having him back at home for holidays and some week-ends.

IAN: *My Mum has been very good.*

ME: *Do you think that's made a difference for you?*

IAN: *Oh it has. Because friends that I've got on other wards, and they haven't got families to help them out, I seem to do better than they are now. They never get any visitors or anything. Some people just don't care and haven't got anything to look forward to.*

Ian, interview 4.

Lenny, Mabel, Matthew and Mike all come from large families and had at least one sibling who continued to visit them, take them out for day trips and provide them with new clothes and other treats, even through long periods in hospital. They all valued this as an important link with their pre-illness lives, with the outside world and with their places within the family.

The combined impact of policy changes [from separated asylums to integrated care in the community] and of differing family situations and ability/willingness to act as informal carers, can have a radical effect on people's self-image and place in society.

Carole, Harry, Irene, Mark, Mary and Jane had all experienced only intermittent periods of three to six month hospital in-patient stays and had

managed to sustain their marriages and to rear families of their own. Ian was living with his partner, Laura, in the hospital grounds. Linda lived with her young daughter. For them all this meant they had valued social roles and networks as spouses or parents.

Mabel, Mike, Lenny and George, despite having the same diagnoses, had all spent many years as hospital in-patients during which these valued social roles had been severed. They all felt very bitter about this loss which they had suffered as a direct result of their illness and the service, and family, response to it at that time.

MIKE: *But, you see, they whipped us in here [psychiatric hospital], and once they got us on the register, that was the end. I was working at the time, in the Dale, where my house was. You bugger, they come for us there, in front of me family!! Took us away! And they weren't policemen. I said, "Do you know what you buggers remind me of? The NKVD -the Russian secret police." But there's no objection to them, Once they get things set, like the Jehovah's Witnesses, there's no argument. So they pulled us in there, away from me family and all of that. I've got two children, you know. A boy and a girl. Nice little kids they were. And then it was all gone. Just like that. I mean, as a register, as a register in your life. I was married. You've got to know where your people are, surely to goodness, as a certain amount of fixture in life. So that you know where you are. I'm not asking them for money or anything like that. It's just that I want to see what I made, my own....my own kin and my wife.... All gone.*

Mike, interview 1.

MABEL: *It was when my husband told us that he wanted a divorce [when Mabel was in the old psychiatric hospital]. I went berserk.....I did! He told my doctor to tell me that he wanted a divorce. He couldn't..he hadn't the face to tell me hisself. He's dead now, poor soul, but I keep thinking, "Why did he do such a thing to me? I'd been so kind to him." It's cruel. And when I had to go to court I just couldn't do it. Somebody from the hospital went in my place, which was nice of them. But when he divorced me, I thought that was the finish. It was such a terrible shock. It's so cruel.*

Mabel, interview 1.

Darren, a young man with schizophrenia who has, even now, spent five

years in hospital, echoed this theme of the cruelty involved in being forced to leave your family home.

DARREN: *Community care's the right thing. You're better off at home. They should all be at home with their mothers and fathers, and take their tablets there, It's not natural to separate families. It's cruelty. They shouldn't be here, where you don't know anyone, and you get hit by patients with big rings on, whatever age you are.*

Darren, interview 1.

Many people, then, saw their families as an important source of help and support and their response as one of the ways in which they were able to "place" themselves within society. They could provide a caring web around them: Although, as Paul points out, webs can both support and entrap those within them.

PAUL: *I know for a fact that, if I was ill, I wouldn't use the hospital.*

ME: *What would you do then?*

PAUL: *I would ask for help. Cry for help.*

ME: *Who would you cry to?*

PAUL: *Family, I think, first.*

ME: *Would they be able to help you?*

PAUL: *Oh yes. In a way. Although it can be a big strain on families. You know? But it wouldn't be straight to hospital, like some of them do.*

Paul, interview 2.

Descriptions of themselves as a "burden" on their families were widespread during the interviews. People were very conscious of the fact that their families found their illness stressful and did not fully understand its nature, and so they wanted to protect them from it, as much as they could.

ME: *So you said that you haven't got a carer?*

BARRY: *Not really, no. Except a Social Worker, and I don't think of them as a carer really, because they're just like a drop in the ocean.*

JOHN: *Well, there's your mam, like.*

BARRY: *Yes, but she's that old now, you know. They get that old that they can't really do much with it, and they don't understand either. In fact, I try to keep a lot of it from my mother now because, if I get on the phone and say I'm depressed, which I have done, she just gets upset and bursts into tears and says, "I can't do anything." And she's got her own problems.*

JOHN: *Yes. So it gets to be the sick looking after the sick in that case, doesn't it? You're not getting the support of the well person. You're getting the sick looking after the sick.*

BARRY: *You've got your sister though, haven't you?*

TIM: *Well yes, but I keep a lot of things up here. I never really articulate everything that's wrong with us, because I'm afraid that it's getting too much of a burden, you know? I tend to keep things back. I think she's got family and that....other things to sort out.*

Barry, John and Tim, group interview 4.

JOHN: *Well, but if your partner can't cope, then you're putting that person in a dilemma, aren't you? So you have to think about whether they could cope with that. They might give up altogether, if you told them too much.*

GARY: *Yes. I mean, I had a bad patch a few weeks ago. It lasted about three weeks and I was just terrified and paranoid the whole time. And I went to my parents like, but I felt as though I couldn't really talk to them because.....because of all the stress that you're putting them under. You put them under enough stress just by being there anyway, because they know why you're there, but they might not know how to cope with it or how to help you out. You know, my parents still think I get a little bit low, or I can't be bothered!! After all these years! All these years! I keep telling them!*

John and Gary, group interview 6.

IAN: *In 1990 I left home. My mother got sick of us. She couldn't cope with us any more. She wanted to get on with her own life.*

Ian, interview 1.

The care, support and social links offered by families are important to

the people in this study, as to most people. However they are also aware of the limitations to that care and of the way in which the onset of their mental health problems has now given them a different role within their families; an awareness of themselves as a burden to others and a stressful influence upon their families' lives.

Four people openly spoke of the way in which the long-stay hospital can itself come to provide some kind of a substitute for the family.

Irene and her husband Dennis recognised the importance of maintaining their family unit. They are an articulate and wealthy family with many years experience of using their local mental health and social services. When reflecting on their circumstances they are conscious that other people many be in less auspicious situations.

DENNIS: *The system's working well for us now. I can get some sort of assurance that, if we get a crisis, then the system will cope, and it takes the pressure off me...which is, frankly, very nice. It makes it easier for me, and I hope then, indirectly, for Irene. Yes, if you've been at the system long enough, then you can work it. But if I wasn't here, or Irene didn't have a base like this and was just living in a room, a rented room in one of those awful places, with no-one to care.....Who would help then? That's a much bigger problem. I know, because I've spoken to these people at the hospital and so has Irene, they almost dread coming out, because where are they going to go to? We look forward to coming home, don't we? But some, and I've got to know some of them quite well over the years, they've said to me, "Where will we go?"*

Dennis [carer], interview 2.

IAN: *Having this long stay in hospital has been what's helped me most. It's been tough, but I class this as my home now; this house and the hospital, even though my parents live just nearby.*

ME: *Do you still have contact with your family?*

IAN: *Oh yes, yes.....But I class this as my home and family, because I've been here now for, like, ten years, and I know the people around here. It's alright, once you get used to it. It takes a lot of getting used to, but, yes, I like it. There's always plenty company*

Ian, interview 1.

MIKE: *Well, you see, when I was in there that long [psychiatric hospital], and I got so used to it, it was my home. That hospital was my home. It was like a big family. They were good, but they treated us just like little children. You know, the nurses in the hospital, they're not relatives. They do very, very much for you, but they're not relatives. You couldn't take it because they had a world of their own with the medical work. You can't replace your home, however lovely. Your relatives have a bond that's more than blood. And now I go through all my life saying, "What the hell are they going to do without me?"*

Mike, interview 2.

MATTHEW: *I liked it [hospital] the way it was. They never bothered you like, you know? They just let you get on with whatever you wanted. We were all like a big, happy family up there. We used to share the nurses tea-bags and coffee and whatnot, up there. You always felt very welcome, just like one big, happy family.*

Matthew, interview 1.

The questions posed by these excerpts from the interview transcripts are still unanswered. How is the current mental health policy to provide backup and support to all families in order to enable them to continue to offer their valued care and support to their relatives? What substitute can it now provide for those without [supportive] families? Where are people with mental health problems to be, physically and socially, in our communities? Is there any desire to break out of the perverse incentives that currently encourage them to remain ill and separate?

9.3.3 Relationships with friends

My friends forsake me like a memory lost.

It was clear from the interview discussions that people's relationships with their friends and friendship patterns had, like those with their families, been disrupted as a result of their mental health problems.

Many people had lost touch with all their pre-illness friends. Gary and Barry are young, single men, with schizophrenia, who have experienced a number of short, in-patient stays.

GARY: *When I first got ill, I thought I had loads of friends, but, ...you know, people slowly dwindled away when they realised I was just gibbering loads of rubbish like,.....and then, you know,.....Well, when you've*

got all these thoughts being injected into your head and you're.....You go to the shops and you think you're doing something really great but other people...

BARRY: *You shy away from people.*

GARY: *Yes, you do.*

BARRY: *Or they shy away from you, rather. They find you all too much, you know?*

Gary and Barry, group interview 2.

Mike is an older man, with schizophrenia, who has spent decades as an in-patient.

ME: *What about friends?*

MIKE: *Well, there's friends I used to know, until I went in there! [psychiatric hospital] And I've made a certain amount of friends in the hospitals. But the friends, the ones you grew up with and that,....no, I've never seen them for ages.*

Mike, interview 2.

Some people had maintained contact with old friends but found this problematic. Carole, Jane, Mark and Irene, who are married and were interviewed at home, did have friends calling at the house and had more easily been able to maintain contact with them on account of their continuing social links through their spouses and/ or children, despite the disruption of their quite frequent hospital admissions. Nevertheless, it should not automatically be assumed that this was entirely helpful for them, and they did express some ambivalent feelings about these "normal" friends and their reactions to their mental health problems.

ME: *You were talking earlier on about public attitudes to mental illness.....*

DENNIS: *Umm,....difficult....*

IRENE: *Well, people really don't WANT to know. I was ill with a chest infection not so long ago and I was in hospital for a couple of days. Now, EVERYBODY was so sympathetic, and every body said, "Oh dear," and, "Ah" and, "Take care of yourself"..Yet, last year I was in x....[local psychiatric hospital] about five times, and NOBODY, just NOBODY, wanted to know.*

DENNIS: *Other than family*

IRENE: *Well, family did, of course. Yes. And the friends I knew when I was in there. But nobody came visiting, and everybody, when I came back, just matter-of-factly expected me to just pick up my bed and just carry on. Nobody said, "You've been away again." Nobody wanted to know. It just wasn't mentioned.*

DENNIS: *Yes, Irene has talked about her illness more now, to close friends, than she ever has in the past. Isn't that true?*

IRENE: *Yes. But they're not interested!*

DENNIS: *They're not interested, but at least Irene is talking about it...to our close friends and certain relatives....But, you know, most people.....you mention mental illness and,"OH!" shutters come down, and [whispering] they'd rather not know*

IRENE: *Maybe they think it embarrasses me. Yes, maybe they think, "Oh well, we won't embarrass Irene by talking about her madness. Um, we'll....we'll keep quiet." It may be kindness on their part. Well, except for Marjorie. Marjorie I can talk to about anything and everything, and I do. I do sometimes talk to her about this, and she sits there quite quietly, and you don't know if she's listening or not. But she doesn't answer in a relevant way. She'll say, "Do you want a cup of coffee? Do you want a cup of coffee now?" She doesn't really want to know, not to get down to the nitty-gritty. She won't say, "You poor thing, does that happen to you?" She doesn't really want to know.*

Irene and Dennis, interview 2.

Some people now had little concept of friendship at all. Lenny, who, like Mike, is an older man who has spent a long time in the hospital, found it difficult to even think about the concept of having close friends any more.

ME: *Do you see much of your friends now?*

LENNY: *No. No. Nothing really.....I haven't seen them.....oh,.....since my sister's funeral, last year. A few then. But, er.....no.*

ME: *Do you have friends you go around with now?*

LENNY: *Well,.....we have, er,.....we visit from the house. She [the manager of the home] will arrange trips, if we want a trip, like, you know. Yes.*

ME: *Uh-huh. Would you say you had a special friend?*

LENNY: *Well,...you've got to.....you know. I'm social with everybody. I tell you, if I'm walking round the town, everyone's saying, "Hello. How are you?". So I'm saying, "Hello, Ray," or Jean, or Joan, or whatever. You know?*

Lenny, interview 2.

In general, the picture of friendships that emerged from the interviews was that people lost their original friends after the onset of their mental health problems and instead developed friendships with other people with similar problems. They welcomed these new friendships for the reciprocal support, encouragement and understanding they could offer. Like most people, they enjoyed spending their time with others with a similar outlook on life and shared experiences. They particularly appreciated the opportunity these friendships gave for them to be able to be a help to other people, since this rarely happened in their families and original friendships, where they tended to be seen only as people who needed to be looked after and watched over.

ME: *What about friends?*

IAN: *No. I haven't kept my old friends. All my friends are up here now [psychiatric hospital]. There's a few in the community, that have been in here. But, no, I haven't really got any friends that haven't been in here.*

ME: *Do you regret losing your old friends?*

IAN: *I did at first, but now I don't. I'm better off with these ones. I can relate more to them. I get a lot of chances to make friends in here, because there's always new patients coming into the admissions wards. You can go over there and meet them and get to know them. So you can get friends very easily over there. I've made a lot of friends.....*

Ian, interview 4.

MABEL: *I'm going on a trip next Friday with Jean, my friend. She's a nice girl, and she lives around the corner from where I am.*

ME: *Oh yes. Where did you meet her?*

MABEL: *In the hospital. She was on the same ward as me. Then she got moved out into a flat, sharing, and then she got a place of her own. That was where I first met John too. He had been in the hospital, but not as long as what I was. It's marvellous how you meet up with people there.*

Mabel, interview 2.

ME: *You said they always made you feel very welcome at the hospital?*

MATTHEW: *Uh-huh. I made a lot of friends when I was up there, like, and I still go and see them yet. A lot of them live in the town and I generally knock about with them. Go for a pint with them, or go to the cafe for a cup of tea. And I know some from the hostel too, G....I know them all there too, like. I generally pop in for a cup of tea and a chat. I was told I could drop in any time I like there. And, like I say, I've got friends from the hospital in the town too, and I can pop in and see them. I haven't got any friends where I live now, but at one time I did have a lot. But, yes, I made loads of friends in the hospital.*

Matthew, interview 2.

However, people also had some concerns about the appropriateness of these newer friendships. Partly this was because they did not feel as though they had altogether chosen them, but rather had them thrust upon them because of their illnesses; partly it was because they were worried that continuing with these comfortable friendships might be standing in the way of their ever fully returning to "normal" society.

LINDA: *That is one advantage of getting into the system and coming to the day centre..... but now I'm frightened to mix....except with people that's more or less got the same problems as me.*

BARRY: *Yes, it's a vicious circle, isn't it? It's a good thing and a bad thing, because you feel comfortable, but alienated from normal....I remember, when I was working at the factory, I felt more normal. I'd go down the pub and things. But, with coming here and finishing that, I feel,.....do you know what I mean? You feel it's harder to get back into that again.*

JOHN: *That's a failing of here, you know. You get into a group where you're comfortable, say a group like this here. Now, how do we get out into society as a group, to talk and mix again?*

GARY: *To talk about what though, you know? It's all very well sitting here and talking about mental health services, but once you get out into society, what do you talk about? I find it very difficult. I tend to just make jokes and that. But when it comes to serious conversation and things like that, I'm just hopeless.*

LINDA: *I've always said this place should have a rehab. centre of its own. It's too safe sometimes. It's a safe place. You come in and feel comfortable sitting here and you can end up so you don't want to get out, because it's so comfortable here.*

Barry, Gary, John and Linda, group interview 3.

And so the normal range of interactions with family and friends that the service users desire as a way of providing a valued place for themselves within their communities is not available to them, on an open and honest basis, at the very time they have most need of its support.

ME: *What have been the most important things in your life?*

MATTHEW: *Well, my friends like. I always had loads of good friends. And I've still got friends down at the day centre. I haven't got many here any more; they're all gone now. But friends, yes.*

Matthew, interview 3.

Much service user focussed research reinforces Matthew's emphasis on the importance of friendship, for example The Sainsbury Centre report "Relative Values" found that service users placed a much greater value on support with the social and practical aspects of life in the community than did their family carers or professionals (Shepherd et al. 1994), and in Barham's study of people with schizophrenia friendship links are described as being "as vital as they were tenuous" (Barham & Hayward 1991).

This lack of a wide range of friends was felt, or voiced, most keenly by those people who took part in the group interviews at the day centre. This, no doubt, reflects both their past experience [of only short in-patient stays] and their current situation [half-way between the asylum and the community, and with access to a service user group]. They are beginning to point to not only their own social shortcomings but also the way in which these are exacerbated by the way in which community mental health services are provided and by the public response to madness, both of which in fact encourage them to stay where they are rather than to seek wider community integration. Given the current situation, it could be a wise "choice" to seem to stay very ill.

9.3.4 Wider social relationships

The problems that people had highlighted with regard to their families and friends –their lack of understanding of mental illness and the stress that it placed upon their relationship– were magnified when it came to wider social relationships. All of those interviewed for the study were aware of other people's fears of mad people and of the way in which, because they associate them with dangerous and unpredictable behaviour, they prefer to avoid their company if possible or watch them closely if not.

LINDA: *People are frightened of us, man. The people that are putting the users into the community aren't doing enough to advertise that it's not a bad thing. They're just putting people into all the bad areas and then....*

BARRY: *No, but it worries you, you know, because you think that people will be looking at you and thinking that you're mad or something like that,....or that you're crazy.*

Linda and Barry, group interview 2.

ERIC: *Mental health has always been a problem that's swept under the carpet though. People don't want to know.*

ME: *I wonder why that is?*

BARRY: *They're frightened.*

LINDA: *There's that much bad publicity about it.*

BARRY: *They're more frightened now, I think. They were beginning to get a bit more tolerant, but then there were all those outbreaks of violence and that, you know? The outbreaks of violence among schizophrenic people are very, very low. It's a lot lower than the average person in the population. But I've seen, because of these attacks, these murders, that the public listen to that and now they think that everybody's got like that. It's changed completely.*

Eric, Barry and Linda, group interview 3.

Indeed, those interviewed probably held such views themselves before the onset of their illness. It is these, internalised, views on madness that help to make their own diagnosis so shocking.

ME: *You said earlier on that you found it very shocking when the doctor finally said to you, "You've got paranoid schizophrenia." That it made you cry and was a very hard time for you?*

IAN: *Yes. As I say, I didn't think that I had anything wrong with us.....Well, I knew I had.....I thought.....I knew I had cracked up.....and, er,.....when she, when she said that I had that, I thought it was very shocking, you know, because I had heard of people going about murdering people in a schizophrenic mania and that. You know? .....It's a shocking thing, to think that's you.....[silence].*

ME: *Umm.....What went through your mind when she said that? What did you think she meant?*

IAN: *It's frightening. Murderers in the streets. It's really frightening.....[sigh] And most people would think that, wouldn't they? They're very ignorant, a lot of people.*

Ian, interview 3.

Given that they know people tend to hold such views on mental illness, they immediately face a dilemma in any wider social interactions: should they disclose their own problems?

JOHN: *I think that really people are frightened of mental illness, and they're frightened if.....just in case they might be dragged down by it too, like....*

BARRY: *You're right, so I try not to.....you know, you're frightened to mention that you've got problems. In case they're going to tell you to get lost or something like that. And then they're going around telling the other neighbours that you're a .... "he's a pest him," and things like that. So you can't ask them for help at all, like normal people would.*

Barry and John, group interview 2.

ME: *So would you tell people that you have mental health problems, or would you try to hide that?*

JOHN: *Well, I've tried to hide it, but I've said near enough what was wrong with us, like. And they've accepted that and I was able to make more friends that way.*

ERIC: *Yes, I've found it's easier to tell people I suffer from mental illness because, if you don't tell them, and you do something that's odd by their standards, it's, "Oh, what's wrong with him then?" and the tongues start going. But if you tell them to start with, they're more likely to accept any odd behaviour you've got.*

Eric and John, group interview 4.

Anyone who tried to break out from their circle of "fellow-sufferer" friends quickly had to decide whether to disclose their psychiatric history and risk a swift end to not only that new friendship, but also the possibility of any others in the locality; or to try to pass as a "normal" person and risk being found out. This is a difficult extra social negotiation they have to manage when they already feel themselves to be vulnerable and lacking in confidence. It is hardly surprising that they find socialising difficult; perhaps more surprising is that most people tend to think of this difficulty as a failing in the individual, or even as a psychiatric symptom.

BARRY: *It gets to the point where you can't even get into a conversation, because that needs to be a two-way thing.*

ME: *But how much of that is the illness? Doesn't everyone have trouble with being able to go out and mix well?*

JOHN: *Well, no, most of it is the illness actually, because you become so inward looking with it, er,.....you lose touch with reality like; you're so "self" all the time that you lose touch with the reality outside.*

GARY: *Yes, I don't mix in with people to start with. I kind of sit back and observe....*

BARRY: *Well, I feel like I don't function well in groups. I find it difficult to cope in groups. I feel as though sometimes people aren't interested in me and so, in the end, I stop talking.*

Barry, John and Gary, group interview 6.

LINDA: *There's nowhere I can go like, not even with the bairn, because I've got social phobia, so I find it hard to mix in with other people. Now, if they had sort sort of group for.....like mothers that suffer from mental health problems, that might help me. But there's nothing.*

Linda, group interview 2.

Instead these people, who now think of themselves as poor at establishing friendships and other social relationships, find themselves spending much of their time with other people with mental health health problems who hold the same view of themselves. Naturally this tends only to reinforce their fears.

BARRY: *It works like that here [day centre]. Some people find it a lot more difficult to break into groups and form relationships and associations. And people are frightened here, because they feel vulnerable. The one thing you get with having mental illness is you feel very vulnerable and fragile with people. So a lot of the people here are very stand-offish with you. I'm not a good mixer. And here you get lots of people all put together that aren't good at mixing, and that most need to mix!!*

Barry, interview 1.

BARRY: *Do you find that you've been here for a considerable number of years now, but there's still people that you don't know all that well, although you've spent a lot of time with them? There's a lot hidden?*

GARY: *Yes, I find that. I find that mental illness....it's like a very destructive thing and because of it you're surrounded by all these people, but you can't get close to any of them -or very few.*

BARRY: *Do you feel that too?*

GARY: *Oh yes.....Well, there's a few you can. A few you think, "Oh, I like this one." But when you think about it really, you don't really know many people.*

ME: *Do you think that was different before you got ill then? That you were closer to people then and it's the illness that's changed that?*

GARY: *Well, yes.....it is the illness to a certain extent, because it changes your character and personality. On a bad day, you might feel like your character's been totally destroyed. But...on a good day, I could try to get close to somebody and be really friendly with them..... Mind, when you come here [day centre] you find, and especially with the new users from the hospital that comes here now, you cannot really get close to any of them, because their personalities have been that much destroyed over many, many years of illness. I just hope that doesn't happen to me like.....*

Gary and Barry, group interview 2.

9.3.5 Forming your self

Following the social constructionist line, that our selves are constantly being created by ourselves, in a dialogical response to and with other's creations of us (Taylor 1989) (Fay 1996) (Burkitt 1991), the excerpts from the interview transcripts give an insight into the kinds of responses from others that people with severe mental illness are having to use in their self-constructions. Of course there are always exceptions, but the responses could be briefly summarized as follows.

From the public there is a response of fear based on only negative stereotypes of people with mental health problems; an expectation of violent and unpredictable behaviour; a lack of trust; an ignorance of the nature of mental illnesses and little desire to learn more; an unwillingness to be with people with mental health problems.

From family and friends there is a severing of the pre-illness relationship, which may continue but within different parameters; a response to people based on caring for them and keeping a watch on them as people who can only take, not give, in these relationships. If new friendships are established, they may offer both support and the opportunity to give help to others but will be made only with other people with similar mental health problems, or possibly with lay or professional people with an interest in mental health.

People may get a variety of responses from members of the mental health team, but the dominant one is still likely to be drawn from a medical model that responds to people as patients with an incurable disease; there may be periods of remission, but people will always relapse.[a major reason why alternative therapies are increasingly welcomed; not so much for what they can offer as for the manner in which it is offered]

The final item in the circle of self creation is service users' own responses.

ME: *You asked last time if we could talk a bit about your experience of having mental health problems and how you felt about it*

MARY: *Frustrated. Pissed off. Not fair. Why me? I often ask, "Why the hell me? What have I done?" It makes you so angry.*

BARRY: *Yes, anger, and remorse. It's all negative things about what you feel your mental health problems have done to your life.*

Barry and Mary, group interview 8.

Anger and remorse are only to be expected when people find themselves given these kind of responses from which to fashion their self, and when they find that their own understanding of their self and their experience is so much at variance with others' accounts. If these leave them with a hopeless and unvalued self for which there is little or no place physically or morally in society, how can they value themselves and continue with life? The kind of arguments around identity politics that feminist and anti-racist critiques have given a voice to in other areas (Griffiths 1995) (Stanley 1992) (hooks 1991), were not much in evidence amongst those who took part in this study. Although some mental health service user groups are now beginning to challenge the identity that people with mental health problems are assigned, this had not yet filtered into the consciousness of themselves that people expressed. However many did feel a pride in themselves because they had somehow found the strength and courage to keep going in the face of such adversity.

JOHN: *All the time you have to keep on trying to develop your personality and your character. And at the same time to drag your self up. And what happens is, your character says no, and your personality drags you back down, and you've got to fight to get back up again. Its a constant changing, and constant returning to the past, and then going forward again.*

John, group interview 2.

JANE: *I think, as far as mental illness is concerned, I think sometimes it is quite hard to.....feel strong, because one is subject to such a lot of slings and arrows, and people who may stick one in the heart, metaphorically speaking. It's hard to consolidate and.....hold on to the joyful things in life. Sometimes it's shrouded in this.....no, I shouldn't say badness, but cloudiness.....of how one relates to others in the world.*

Jane, interview 2.

IAN: *And in the four years that I've been in hospital I've learned how to manage better with my illness. I'm a stronger person now than what I was before the illness took hold of us. I don't take overdoses any more, and I don't.....I'm much more well. I'm more level than I was before. And it's the long stay that's done that. It's been really tough, but you learn to cope better. The longer you stay in, you get better coping strategies for yourself.*

Ian, interview 1.

MABEL: *And I was on all the different wards, but it seemed as though I just couldn't cope, couldn't cope with myself.....But once I did cope with myself, well.....I am getting better, but it's after a lot of years, a lot of years.....It was a long, hard struggle, but I managed it in the end. But it took us.....it was such a struggle, I tell you. I felt as though.....you know.....how you think about what's happened to you, and you think, "Could that happen to anybody?" [incredulous] But it did! It happened to me! And now I've got out and I'm living in a house of my own again.*

Mabel, interview 1.

To continue with daily life in such circumstances is indeed a hard struggle and one that asks for courage and determination. It is both wearing on a daily basis and hard to sustain much hope for any improvements in the future in the face of such contrary messages about your worth to and place in society. However hard people try to hold on to a better vision, the gloomy accounts and forecasts of others tend to turn into self fulfilling prophecies as they watch themselves and others continually failing and relapsing.

Perhaps Ian and Mabel are among the most vocal about their courage and determination because they have both also experienced utter despair about themselves.

ME: *He [Ian's friend] was in the hospital twice a month through overdoses?*

IAN: *That's right. And I did.....[swallowing hard].....You know, you get depressed,.....everybody gets depressed, but when you've got an illness like what we've all got, the depression can be suicidal.....Do you know what I mean? You're just sick of your life, just sick. You feel as though it's getting worse and worse. You just feel as if you're existing, that's all. You feel as though.....there's nothing to look forward to, and you get really depressed.....Anyway, it's got a bit better again lately*

and I feel a lot better. It's a long time now since I've been suicidal. I don't think I would take another overdose again, because waking up in the hospital with a tube down your throat and.....it's not a very nice feeling. And being restrained while they put another tube down you, and you're trying to fight them off, to keep them away, so that the tablets can do their job. And then you come round the next day, and you're usually high from all the tablets you've been taking, and you fall out of bed and you crawl on your knees across the floor, and they keep putting you back in bed. No, it's not very nice.

ME: *What do the staff do after that?*

IAN: *Well, when you've pulled through from the overdose attempt, they usually search for your GP, your doctor, and he'll come and tell you.....he'll come and lecture you about what you should be doing and have a chat with you and then you're discharged back into the community, or wherever you're going.*

Ian, interview 3.

ME: *Are there any things you wanted to ask me?*

MABEL: .....*Um, shall I tell you about when I cut my wrists? No. Just forget about it.*

ME: *Well, you can tell me if you want to.*

MABEL: *Well I was just sitting and I was really depressed. I just got the knife and.....I didn't cut really hard, because if I had I would have killed myself then, I know I would. But.....it was just one of those things. I felt that way.*

ME: *When was this, Mabel?*

MABEL: *Before, before I went out. I should put it behind me really, shouldn't I? But I keep thinking, "Why did I do it?" I was feeling really depressed at the time. Really, really. I just couldn't cope with nothing more. I just felt as though I couldn't do anything more and that was it. I felt that was the end. But I've always been very independent. Always. Trying to do the best with myself. I've always tried to do the best. As much as I could....Eeh, it's a bad job you're getting, trying to understand me! I try to understand. I think....."Why did I do it?" I do. I just think. "Why did I do it? Was that really me?" Especially when I'm sitting on my own of a night time. I keep thinking.....*

Mabel, interview 1.

9.4 Discussion

9.4.1 Social networks

The gradual move to a policy of community care for people with mental health problems has been accompanied by an increasing amount of research into the nature and importance of people's social networks. The term has been conceptualised in a number of ways, but is generally understood to refer to the web of relationships attached to an individual (Forrester-Jones & Grant 1997). These are taken to be an important part of achieving the aim of recent community care legislation viz. "to enable people to live as normal a life as possible in their own homes or in a homely environment in the community" para. 1.8. (Department of Health 1989). The vision for such a policy in the 1990s was one where people would not only receive care but would also participate in its planning and delivery and in general community life. This was a vision not yet realised for those who contributed to this study.

Studies that focus on the self perceived needs of people with learning difficulties or mental health problems now living in the community have also highlighted their concerns about their lack of freely chosen leisure activities and social relationships. The findings from this study therefore both echo and add to this wider research picture. All the participants had ambivalent feelings about their social networks and daily lives and concerns about what they perceived as their lack of social skills. Looked at from another angle it could be argued that the main barriers to enlarging their social networks and thus increasing their social skills lies within the way that community mental health services are provided. The current priorities would seem to

be providing organised day time activities and accommodation, rather than enabling people to develop and maintain their own social networks. Whilst these various priorities need not be contradictory, in practice they seem to be, leading, as shown in this study, to what has been described as "the ghettoisation of friendship" (Richardson & Ritchie 1989) –a situation where people are seldom alone, but often lonely, because they are not in the company they would, ideally, have chosen

It would seem that there is a need for further research to clarify the meaning, importance and nature of friendship for people with severe and enduring mental illness, since these are not yet clear from current readings of either quantitative and qualitative studies. There would appear to be differences from those of the general population, perhaps not surprisingly while the life courses of people with mental health problems are still so different, both geographically and emotionally. Without this understanding the danger is that researchers continue to ask the wrong questions; again the analogy might be with developments in the mainstream [of psychology, philosophy and anthropology] around the concept of the self before it was questioned by feminist thinkers and shown to be based on the white, middle class, Western, male self, and therefore of limited interest and concern to women [even if still white, middle class and Western.]

The implications of the importance of social networks as part of successful community mental health care have been picked up in a number of reports, for example Louis Blom-Cooper's report on the murder of Georgina Robinson. Speaking of the need for a review of the 1983 Mental Health Act he writes:

> It focuses not on patients but on doctors. Successful care from the patient's point of view, however, enables him or her to lead as normal as life in the community as possible. Other aspects of care and supervision –such as a good relationship with a key worker; the provision of social and educational opportunities, a congenial place to live and adequate financial support– are prerequisites of rehabilitation. These elements are as essential for the wellbeing of a seriously mentally disordered person in the community as depot neuroleptic injections (Blom-Cooper et al. 1995).

9.4.2 Social selves

The atomistic ideas of human beings as single, self-contained and self-directing entities, which are prior to society and form the basic building blocks of social relationships, are deeply rooted within Western thought and culture. Nevertheless, they are increasingly being challenged by those who view the self

as being, at least in part, both socially and culturally constructed. They argue that our identities are formed by and within the social relationships in which we must exist and are closely bound up with our particular culture's discourse and language. It is these that bind together any social group and are primary to the formation of our self conscious identities (Burkitt 1991).

At the same time, the burgeoning interest in self, identity, narratives of self and autobiography, as well as questions of representation and authorship across the disciplines within the human sciences, has led to an increasing recognition of the role of identity politics –the acknowledgement that who we are and how we feel about ourselves are never just neutral facts or biologically given but, rather, crucially influenced by powerful personal/ social/ political others in our lives.

> The self I am –the identity I have– is affected by the politics of gender, race, class, sexuality, disability and world justice. In other words, the feelings I have, the reasons I recognise, the wants I act upon –they are all deeply political (Griffiths 1995).

These understandings of the formation of the self are of crucial importance for the development of community mental health services and have implications for the lifestyles and attitudes of us all. During our lives we may make ourselves, but we do not do so freely in conditions of our own making. We all think about ourselves and others but within ideologies already generated by power relations within our history and culture.

> When we enter human life, it is as if we walk on stage into a play whose enactment is already in progress....and that casts us as its playwright but takes place on a set that almost entirely conceals its own artifice. In truth the authorship of the "I" is, at least in part, elsewhere. Our stories make us as beings who make ourselves but there is only a limited sense in which we can chose our own story and determine our own plot (Greenberg 1995).

We all need others to become ourselves but, at the moment we seem content to make some people "The Other" and to exile them to undesirable social roles and physical locations: As Barham points out, people with severe mental illnesses are currently doubly excluded from society, both through their negatively constructed identity and through their impoverished material conditions.

> Taken together they locate the social fate of the ex-mental patient within the twin themes of identity and structure and bring into sharp focus two distinct but closely interconnected ways of being

shut out from membership of the larger society, two facets of a process of devaluation that is exhibited not only in how people are seen or represented but also in the structural options made available to them (Barham & Hayward 1991).

10. CONCLUSIONS

10.1 Introduction - the structure of the thesis

This thesis has traced the evolution of a grounded theory study undertaken for the award of Ph.D. The main aim of the study was to examine the experience of severe mental illness, and of using mental health services, from the perspective of service users. Grounded theory studies have shown themselves to be most useful when, as here, the concern of the research study is to examine people's experience of a particular phenomenon. Such studies aim to develop an inductively derived, empirically grounded theory about a particular area of study by focusing upon those categories and issues which seem most relevant to the emerging data. In this way the study's findings and explanations are more likely to be data-driven and grounded in the participants' own experiences, terms and meanings. [See discussion in Chapter Five]

Consequently this thesis has adopted the written and temporal format most in sympathy with this research approach, in that, whilst its early chapters trace the development of mental health policy in Britain, in order to provide an understanding of the context in which the experiences that its participants describe take place, they do not aim to provide a comprehensive review of the bodies of relevant literature. Rather they aim to provide a flexible and open-ended introduction to the research area, allowing the researcher to approach the study with "an open mind, if not an empty head". For grounded theory is essentially an analytic approach directed towards creating categories from the data and analysing the links between them. Unlike logico-deductive research approaches, it does not begin with a hypothesis derived from existing theories, which must then structure its data collection and analysis. Just as the data must be rooted in and shaped by the participants' experiences and understandings, so too the researcher must be free to adapt the data collection and analysis correspondingly, without being constrained by pre-conceived hypotheses and conceptual frameworks. Wider reading of the existing literature, and integration of the study into it, will thus need to

come much later in the study, as recurrent themes are pursued and developed through further data collection and analysis.

Therefore this study will conclude, as is usual in grounded theory studies (Strauss & Corbin 1990), by answering its research questions through setting out the arguments developed in its three parts [the history of mental health services in Britain over the past two hundred years; the development of social research methods; the participants' accounts of their experience of severe mental illness] and then linking these three discussions into an overall argument which also draws out and elaborates upon the key concepts to emerge from the study. Finally the chapter discusses some implications of the work for future research.

10.2 The context for the participants' accounts: the development of mental health services in Britain

The argument developed in Chapters Two -Four shows that many people and organisations in our society have an interest in mental health. Politicians, psychiatrists, policy makers and mental health practitioners of all kinds, as well as members of the wider public, have all held strong views on the aims and directions which mental health policy in this country should be adopting. Historically they, rather than those deemed to have mental health problems, have been the people with the power to "name" mental distress and to shape and direct the response to it.

These early chapters of the thesis traced the debates of these various, professional interest groups over the past two hundred years, revealing the way in which, although different ideas and policies have come and gone, and then come again, the continuity which underpins them all and allows them to roll on is uncertainty about how mental distress should be conceptualised and responded to.

For at the heart of the problem has been, and continues to be, the lack of any clear and universally agreed definition of lunacy/ madness/ mental illness/ mental health problems .... as evidenced by its changed and still changing names. Of course it is difficult to provide a service for something which cannot even be named without argument. Different explanations, definitions and conceptualisations have always co-existed, with some more dominant than others at particular times. For most of the period covered by this thesis, medical dominance has held sway and a largely medical and physical discourse has succeeded the religious and moral discourse of the previous

centuries. However there continue to be signs of competing discourses, including some now based around sociological and political concepts, and a new language is developing. Centred around ideas of equal rights, the social model of disability and of an integration based on difference, it forms a powerful tool for challenging traditional conceptualisations and building new ones (Morris 1991) (Barnes & Mercer 1996).

The current dilemmas and tensions in mental health policy and practice are understood better when viewed across this long period of time. Mental health services, by whatever name, mark out any society's understanding of, and response to mental distress. Consideration of the history and current state of these services, as set out in Chapters Two, Three and Four, both situates and helps to explain current thinking, controversies and problems in the provision of the services which, in large part, structured the experiences described by the participants in this study.

In the confusion that results from attempts to develop strategies and services for an "illness" that cannot be defined, Lindsey Prior, in his study of the social organisation of mental illness, has adopted the opposite approach, of defining what society thinks mental illness is at any one time by examining the services and spaces provided for it (Prior 1993) and this has proved to be a valuable perspective in the development of this thesis. In this way the mis-match between the physical, social, moral and economic spaces made available for mental illnesses over the years, spaces which have been marked out as a result of negotiations between various professional groupings, and the spaces which service users themselves would mark out becomes very clear.

From whatever angle the definitions and conceptualisations of mental illness are approached, it is clear that they are contested even within and between the groups such as politicians, psychiatrists and the public who have, until now, largely dominated the debate. Meanwhile the views of those people who live with severe mental illness still struggle to be heard, acknowledged and acted upon in the midst of so many other powerful voices.

This confusion in policy for people with severe and enduring mental health problems and the exclusion of service users' perspectives thus set the scene for the research area addressed by this thesis, which was to examine the experience of severe mental illness, in light of the claims made for the policy change to community care, and from the perspective of those people who live with it.

Policy documents for health and welfare services in the 1990s [see discussion in Chapter Four] seemed to provide some openings for the inclusion of the views of service users in the planning, development, delivery and evaluation both of their own care and of wider services and support. The introduction of "markets" into welfare provision and of the language of consumerism

focused attention on the need to provide "user-centred services", which entailed professionals first agreeing with service users what were their needs. The introduction of requirements for both the health and social services to carry out local consultations on their plans for service development and to develop user involvement helped to establish the idea that service users are also stakeholders in these debates.

10.3 The participants' accounts of life with a severe mental illness

The argument developed in Chapters Six - Nine is based on analysis of the data generated in the interviews, which were conducted during the fieldwork for this study, with service users in one county in the north of England. These chapters draw out and develop the participants' accounts of their lives and of their experiences of using mental health services.

Once we begin to include the views of mental health service users in the debate on the nature of mental illness and the best response to it, it becomes very apparent that their conceptualisations of mental illness are very different from those of politicians, mental health professionals and the general public. Consequently their views on the efficacy of the services and treatments provided are correspondingly critical; much more so than for acute physical illnesses, where service users and professionals tend to be working from shared templates and constructs. The "spaces" which service users would mark out and provide for people living with severe mental illness would have a very different shape and function from those currently devised as an outcome of the negotiations amongst professional and public groups.

Of course there is no one user view, any more than there is one professional or public view. In addition, mental illness is an extremely broad term and people who suffer from anxiety or depression may have very different views and experiences from those with schizophrenia or manic depression, who contributed to this study. Nevertheless the interviews conducted as part of this thesis suggest that there are striking differences between what these service users want and what is currently provided for them. For ease of reading the participants' accounts, although experienced as an interlocking and self-reinforcing whole, were explored in these chapters under four main headings: staff; treatments; daily life; self and others.

10.3.1 Staff

If service users had the dominant voice in designing mental health services they would provide for staff a very differently shaped template or "space" from the current, professionally dominated one. In their discussions of professional staff it was clear that service users would prioritise personal qualities, such as a genuinely caring and respectful attitude, cheerfulness, and excellent listening and communication skills, in all staff. They want staff who are a pleasure to be with because they are attentive, reliable and view service users as other adults. In structural terms, they would appoint these staff to positions where they are supported in this style of working, for example by having only small case loads so that they have enough time to develop trusting and continuing therapeutic relationships with service users; by being employed across agency boundaries, so that they can respond to whatever problems service users identify as important to them; and by being available and easily accessible at the times when service users need them. They would expect them to be knowledgeable about mental health problems, treatments and services but as a source of advice and suggestions, not coercion.

Thus a clear vision of the ideal member of staff, of whatever profession, emerged from the interviews. The particular qualities that service users valued in staff were: having a cheerful and lively personality; having a genuinely caring attitude; having the time and ability to really listen to service users; being well-known, reliable and easy to contact; and being knowledgeable and a good communicator. These qualities were identified as crucial because they provide the foundation for the trusting, open and safe relationship between service users and staff, which the participants saw as vital to their needs.

The gap between the participants' hopes and their experiences was clearly shown by the fact that they rarely experienced their relationships with staff in this way, although when they did they valued it extremely highly. Actual staff could rarely fit the template that service users would devise. On the contrary the participants' experience was that staff: are difficult to contact; are available only in office hours; are generally short of time; frequently change jobs; may lack specialist knowledge of mental health; are trying to carry out conflicting roles; are not good communicators; and must prioritise compliance with treatment regimes and have the power to section you. Overall these make it extremely difficult for service users to form the open, trusting and safe relationships with staff that they so much desire.

This gap between hopes and experiences left the participants facing a difficult dilemma in their relationships with staff. Because of the social isolation experienced by mental health service users, staff members are potentially more important th them than to other health service users (Beeforth

et al. 1994) (Hannigan et al. 1997), yet, because they operate within different ideologies and agendas, many people find their relationship with them fraught and problematic. For example, people often spoke of wanting to be honest with staff about their worries over medication but were too frightened to do so in case they then found themselves being sectioned. Currently staff roles are structured to meet other needs than those of the service users (Barham & Hayward 1991) (Shepherd et al. 1994). The state is concerned with their role as agents of social control and, given the continuing confusion within mental health policy, staff themselves receive conflicting messages about their primary purposes; as advocate or monitor; to support or control (Godin & Scanlon 1997). Service users and staff are often each working to very different priorities and within very different frameworks of belief about the aetiology, course, treatment and cure of mental illness (Rogers & Pilgrim 1997). The participants in this study wanted help when first diagnosed with severe mental illness and generally found that to be provided only by mental health staff. Yet most soon found that the help staff were able to offer was not that which they were seeking and might even make their overall situation worse and trap them within the "mad" world. In this situation they had to weigh up delicate and difficult choices in an attempt to match their ideal staff "space" with any of the staff "space" officially provided.

10.3.2 Treatments

Once again the data from the interviews gave rise to a clear message from the participants about the type of treatment they had hoped for when they first became aware of problems and sought help from the mental health services. They hoped for a treatment that would provide a cure, as they understand the term, without harmful side-effects and that could be delivered in a way that allowed them to feel empowered and retain their self-esteem.

However, in this area of their experience also, their original hopes turned out to be a far cry from their ongoing experiences. The treatments available could not offer such a cure and had many serious side-effects, not all of them physical. Experiencing the many physical side-effects of the drug treatments they were offered was, in itself, unpleasant and frightening but, beyond this, side-effects such as weight gain, loss of sex drive and uncontrollable shaking also made it extremely difficult for people to participate in an "ordinary" life. In addition people then found themselves having to take more medication in order to combat these side-effects, until they came to experience a daily life dominated and structured by their medication regimes; a fact which again contributed to continuing their social exclusion. The experience was often exacerbated by the fact that people did not feel they had been prepared for,

or warned about, these side-effects. This not only made experiencing them very frightening, it also had a deleterious effect upon people's relationships with their clinical care giver: if they felt they had been tricked into taking the medication, they were less willing to take the care giver's advice on future occasions.

In addition the participants were offered a very limited "choice" of treatments, mostly drugs or ECT and, possibly, whether the drugs should be administered by injection or in tablet form, at home or in a clinic. They were given very little information about the drugs and ECT; even less about any alternative treatments. Despite their very different backgrounds and perceived needs, they were all offered much the same treatment regime and had very little involvement in the decision making process, despite what is written in the various local and national charters. Not only did people have a limited menu to chose from, but also they felt they had very little choice about whether or not to accept these limited options. Mental health staff are in too powerful a position and many service users are unwilling to risk jeopardising such help and support as they have been able to achieve through being viewed as a "difficult" patient. All service users live in the shadow of the knowledge of compulsory treatment. This, and the lack of information, leads many to feel that they have been tricked or forced into receiving frightening treatments. This is very destructive of the trusting relationships that service users would like to have, and feel they need, given their lack of other social contacts, with staff.

This style of receiving treatments that could not cure and often had devastating side-effects, with poor information or involvement in planning and decision making, and that were often delivered, whether at the depot clinic or at home, in a dehumanising way certainly did not fit with the participants' original hopes for treatments that were empowering and maintained their self-esteem.

However, service users are not passive recipients of treatments. They are all active agents in structuring their lives. Consequently they adopt various strategies in the light of the situations in which they find themselves and the meanings which they attach to them. Given this gap between their original hopes and expectations and their actual experiences, all the participants thought through similar risk/benefit calculations with regard to the treatments on offer and attempted to resolve the dilemma facing them in a variety of ways depending upon their own situation.

If they decide to accept the treatments on offer this has a number of implications. Firstly, it places people within a medical/disease model of mental illness, although this may not be their own understanding of their problems. Once there they will tend to be viewed as patients, whose aims

and understandings will be secondary to those of their care givers, although they may wish to continue to see themselves as self-determining adults trying to continue to function within their communities by developing ways of coping with their symptoms through utilising a range of biological and psychological treatments and social, practical and emotional support. Secondly, taking the offered treatments colours people's relationships with significant others in their lives, who also come to see them within this medical/disease model and treat them accordingly. Thirdly, taking medication can soon come to command a central role in people's lives and form a major topic of their conversation and thinking. In this way it helps to confirm people's place within the "mad" world. For the central dilemma posed by current mental health treatments is that, far from curing difference from the norm, they may rather emphasise it and help ensure that people remain trapped in the world of mental illness, just as Estroff reported over fifteen years ago (Estroff 1981). Once people realise this, they also come to see that there are many perverse incentives within the mental health system that encourage them to be as "mad" as possible. Some, realising that their contacts with staff are limited to the administration of medication, may decide to stress the severity of their illness in order to have more attention and contact. Others may resist treatment regimes because of the wider, social meanings they attach to them as marking them out as a mental patient, but feel unable to discuss this choice openly with staff working to very different understandings and priorities.

Much of the official discussion of mental health policy is predicated upon the assumption that effective and acceptable treatments are available. This is not the experience of these service users, who find decisions about whether to accept medication or ECT very difficult. They view their symptoms in the context of their whole life not, as many professionals do, in an isolated, medical context. Whilst staff may feel that their priorities have to be assessment, diagnosis and risk control (Lindow 1996) (Corrigan & Penn 1997) (Shepherd et al. 1994), the participants wanted rather to feel free, informed and supported in choosing from a range of "treatments" to fit their particular circumstances and values. Consequently there is a large gap between professional and service user perceptions of what constitutes an effective treatment, and the criteria by which this should be judged. From a service user perspective current treatments may indeed cause what the participants had originally hoped they would cure, both in terms of symptoms and of continuing social exclusion, by undermining their self esteem, disabling their return to a valued social role and emphasising their difference. Once again the "space" provided, this time for treatments, proved a very poor fit with service users' perceived needs.

10.3.3 Daily life

In the interviews, discussions of daily life tended to centre around employment, or the lack of it. In describing their ideal day, the service users wanted a daily life structured like "normal" people's around a job, either paid employment or equivalent, which they foresaw would improve both their material quality of life and their sense of self esteem, a finding which echoes much other recent research (Mental Health Foundation 1994) (Hannigan et al. 1997). Ideally the participants wanted jobs which provided interesting work, a living wage, tolerance of their mental health problems and an environment that enhanced their self esteem.

However the daily lives that the participants were leading at the time of the interviews were very far removed from their ideal. Instead of the kinds of jobs and support that they were looking for, they faced the very limited, and limiting, choice of a life on benefits with sheltered employment, or simply a life on benefits.

Given yet another gap between their hopes and expectations and their actual experiences, people once more faced a difficult dilemma over whether or not to accept a place on a sheltered employment scheme. Sheltered employment schemes are valued because they are tolerant of mental health problems and provide ready access to support, but fail to meet the service users' other three criteria for the "ideal" job because, in their experience, they provided monotonous and menial work, for only three pounds a day and so left people feeling degraded, exploited and trapped in the "mad" world. Those people who had nevertheless decided to take it up had done so not so much as a positive choice as because they felt it was better than nothing. It did it at least give some structure and purpose to the day, offered a place to be and people to interact with and provided a little extra money.

For those people who could not accept the negative aspects of sheltered employment, the only other reliable source of income was a life on benefits, but, in order to continue to receive them they had to show themselves to be sick and unable to work. Consequently they too were trapped in the "mad" world with perverse incentives to stay ill rather than show any signs of improvement. Rather they must trade on their illness to provide work for others, whilst enduring what Brandon has described as "the everyday trauma of eventlessness" (Brandon & Brandon 1995).

The value of work in improving and maintaining people's health and social functioning [a Health of the Nation target for mental illness] is widely acknowledged, yet it has largely disappeared from mental health policy with the move to community based care (Nehring et al. 1993) (Perkins et al. 1997) (Schneider 1998). Rather people's inability to work has been recast as

an individual's psychiatric symptom (Campbell 1997) (McCrum et al. 1997). Genuine work offers people the opportunity to contribute to, and be valued members of, their community. The workplace and the wages grant people access to wider social networks and place them within the same structures of time, space and resources as others, rather than segregating and trapping them in the differently structured world of the mad. In addition the difficult judgments that the service users are having to make concerning their daily lives have ramifications for their relationships with mental health and other staff and for their decisions about treatments. For example, people may decide not to disclose their full mental health problems to staff because they fear that the consequent treatment regime will be incompatible with their current employment, or they may feel that they must overstate their problems in order to remain eligible for benefits. Neither course is conducive to the development of an open relationship with staff or of compliance with treatment. These difficult calculations and decisions can be better understood once situated in this wider context of the other important issues in an individual's whole life. In the area of their daily lives, just as in the areas of staff and treatments, the spaces provided for mental illness do not fit with service users' own templates and serve only to provide them with negative messages and insoluble dilemmas about themselves and their place and value in society.

10.3.4 Self and others

For the participants in this study, the experience of severe mental illness was as much one of a change of self as of having an illness, as that is usually understood: they did not so much have a mental illness as become "mental". This is a harsh and destructive category in which to find oneself placed, and people are "placed" there, since the consequences of mental illness are as much to do with society's response to it as with its primary symptoms. The participants could find almost nothing positive to say about the ways in which their lives and self-image had been changed by the experience of mental illness. Once again there was a large gap between the self they wished to be and the actual roles and relationships that they were able to undertake once diagnosed with a severe mental illness.

People's social relationships and networks were radically altered by the onset of their mental health problems as, consequently, was their sense of self, yet much user-focussed research has shown the preservation of these is precisely the area which service users would like to see given greatest support (Barham & Hayward 1991) (Shepherd et al. 1994). Instead people felt that their families often now viewed them as a burden rather than the

support they used to be; someone who needed to be carefully watched and monitored and with few opportunities for care giving and mutual support. Those whose families had been able to maintain close ties with them greatly valued this for the practical and emotional support it gave to them and for providing a channel to their pre-illness selves and the wider community. Those whose family ties had been broken, particularly through the effects of a long hospital stay, still felt very bitter and distressed about the loss of this important part of their lives and selves.

Friendship patterns had also been disrupted and most people's friends were now also those who were part of the mad world; either other people with mental health problems or members of staff. These new friends were valued because they gave opportunities for both giving and receiving help and support and because they had similar experiences and outlooks to share. However they were also a cause for concern since they had not been freely chosen and were seen as, in some ways, part of what kept people within the mad world; the ghettoisation of friendship (Richardson & Ritchie 1989).

Recent years have seen a growing interest in research into the nature and importance of people's social networks, but these are, as yet, poorly understood in relation to the experiences of people with severe mental illness (Forrester-Jones & Grant 1997). The participants in this study clearly felt ambivalent about their social networks and daily lives. Although they were eager to find support with these areas of their lives, the current way in which community mental health services are provided could in fact be held to be one of the main barriers to enlarging their social networks and maintaining their social skills. This provides another instance where the structural failings of the mental health system are instead too easily dismissed as individual psychiatric symptoms and failings.

In addition the service users were very aware of the powerful public images of madness as violent, dangerous and unpredictable and were shocked to think that they were themselves now subsumed within these images. This formed another barrier to wider socialisation through people's worries about disclosing their mental health problems.

The atomistic ideas of human beings as single, self-contained and self-directing entities, which are prior to society and form the basic building blocks of social relationships are deeply rooted in Western thought and culture. Nevertheless, they are increasingly being challenged by those who view the self as being, at least in part, both socially and culturally constructed. This would mean that our identities are formed by and within the social relationships in which we exist and are closely bound up with our particular culture's discourse and language, which bind together any social group and are primary to the formation of our self conscious identities (Burkitt 1991).

These ideas have fed into a burgeoning interest in narrative across a variety of disciplines and in the concept of the self as a narrative - we are, or become, the stories that we can tell about ourselves, drawn from our cultural menu of available narratives (Reissman 1991) (Greenberg 1995) (Fullagar & Owler 1998).

From the interviews it was clear that the participants were given only images and tales of negative difference and hopelessness from which to fashion their own stories and sense of self. They spoke of feelings of anger and remorse, but also of their great courage and determination in keeping up the struggle to carry on in the face of such discrimination and difficulties. There are many ways in which the current pattern of service provision contributes to, rather than mitigates service users' social difficulties, and service users would like to see areas such as supporting and maintaining social networks prioritised and the structural determinants of their identities as "mental" challenged.

10.3.5 Conclusions -gaps, dilemmas and mixed messages

In Chapters Six - Nine the participants' accounts of life with a severe mental illness were considered. The grounded theory approach adopted by the study meant that it was possible to draw out the participants' accounts of life with a severe mental illness into a general narrative, which could then be used as the basis for interpretation in the thesis as a whole. During the process of the research the arguments and interpretations offered by the participants were themselves further interpreted and developed in subsequent interviews and in the light of the wider sociological literature and theory. It was clear from the interviews undertaken for the study that, once diagnosed with severe mental illness, people faced a gap between, on the one hand, their hopes and expectations and, on the other, their actual experiences in relation to all aspects of their daily lives, including their treatment and contact with mental health professionals. These gaps, and the dilemmas which they consequently posed for people, also interacted with each other to form a whole experience greater than the sum of its parts, which posed even greater challenges to people's attempts to maintain a sense of self worth and to conduct a life worth living.

In particular the three inter-related and interlinked concepts of self, stigma and space came to hold a central position in the study's interpretation of the participants' experience of severe mental illness. The driving force of any grounded theory study is the search for these central themes in participants'

diverse accounts of their experience of, and feelings about, the particular phenomenon under investigation, in order to formulate an overall conceptual framework based in, and generated from, that study, rather than any previous ones. Such central themes serve to illuminate participants' actions and to help explicate their emotions.

The social sciences have display a renewed interest in "the spatial" in recent years, largely inspired by debates and developments within the discipline of geography. For the participants in this study the nature of the social and physical spaces made available to them subsequent upon their diagnosis of severe mental illness had a crucial impact upon their experiences, their feelings about these experiences and, consequently, upon their sense of self. The spaces and localities that society currently provides may fit with public perceptions of severe mental illness as different and dangerous, but are a very poor fit indeed with the participants' own perceptions of its nature and needs.

Goffman's work on stigma and the management of spoiled identity (Goffman 1963) has exercised a lasting influence upon the social sciences, particularly in the area of chronic illness and disability. His definition of stigma as "a special kind of relationship between attribute and stereotype" is based upon the claim that there can be a discrepancy between a person's "virtual social identity" i.e. the cultural stereotypes into which he or she should fit and his or her "actual social identity" i.e. the attributes which he or she actually possesses. Some illnesses and conditions are therefore more likely than others to be stigmatised, depending upon the moral blame attached to them and the degree to which they are visible and known about.The experience of these illnesses and conditions is thus one concerned with managing not only its symptoms and effects but also its deeper significance and meanings for a person's sense of self and identity. In this way many physical symptoms and illnesses come to have attached to them social aspects and meanings, not only for the person living with them but also for society as a whole. Certainly the participants in this study were taught how to be mentally ill not only by their medical treatments and interactions but also, and more importantly, by the consequent changes in all aspects of their social relationships. Physical symptoms had clearly led to negative social transformations for them and the management of their new social identity as "mental" proved extremely problematic. Their own sense of stigma and spoiled identity [felt stigma] was marked out and maintained by the social, moral, economic and physical spaces made available to them [enacted stigma]. These spaces severely limited the stock of narratives upon which they could draw when forming their selves and talking about themselves as people with a mental illness, and helped shape the negative reaction of other "normal" people to them.

For these participants being mentally ill was clearly as much a moral identity as a health problem, a cultural issue, not simply a personal one.

The biographical disruption caused by chronic illness, and the various strategies which people adopt to deal with it, have also been the subject of increasing interest in the social sciences in recent years (Bury 1982) (Corbin & Strauss 1988) (Radley 1993). By enabling the participants in this study to tell their life stories during the interviews it was clear that they had experienced almost overwhelming threats to their autonomy and self-identity as a consequence of developing mental health problems; threats which were harder to withstand than those experienced in the context of most physical illnesses.

When taken as a whole, the participants' descriptions of the experience of severe mental illness make dismal reading. It is clear that these service users continued to be socially excluded regardless of where in the county they lived or received services. Furthermore they experienced the current provision as a trap, which, whilst offering some help and relief with symptoms, also prevented them from returning to ordinary living. Although they received rhetorical messages about cure and integration, their practical and emotional experiences were about it being in their best interests to stay ill for, until wider cultural changes take place, the integration on offer is not a desirable one, in a community that does not want them and provides no valued social role or space for them. In these circumstances, and with the current inflexible mental health system, which sees people as either well or ill and targets resources upon those who are most ill, people are afraid to get well, or even "better", and may rather decide to make best use instead of the mad world in which they now find themselves; what Estroff has described as "flexing their psychiatric muscles" (Estroff 1981). Many of the participants in this study described their experience, the space which society made available for them, as a vicious circle in which you can start at any point and still get nowhere.

GARY: *People don't want to come to this day centre. They see it and us and think that it's not nice, but they don't understand that there isn't any help anywhere else.*

ERIC: *But they couldn't make it too nice or too many people would want to come here, wouldn't they? They would think that it's better to be ill than to be well.*

BARRY: *Well no, it's not good enough here, but it's the only place where I feel part of anything, here in this place.*

LINDA: *It's not good enough, but it's safe, too safe. The only help and support is here. If we got better we would lose all this, and for what?*

ERIC: *People pretend to be more ill than they are to get in and people pretend to be less ill than they are to stay out! People get things they wouldn't otherwise have because they are ill and people lose things they would otherwise have because they are ill. We all want to be better, but being ill can feel nicer than being better.*

Gary, Eric, Barry and Linda, group interview 4.

The policy change to community based treatment and care, which had occasioned such debate amongst mental health professionals, policy makers and the general public and consumed so much of their time and energies, had scarcely impacted at all upon these participants' core experiences of life with a severe mental illness. Their central concerns, gaps and dilemmas remained untouched.

10.4 The research approach and methods

Besides examining the experience of severe mental illness, a second, and parallel, aim of this study was to consider the development of research methods that allow the voices of service users to be heard in both academic and policy settings. In recent years researchers have been encouraged to include service users as partners in their work;

> Patients are on the receiving end of what the NHS is all about. They know the services best and their perspective should be regarded as an essential element of all NHS research. In future, all researchers working for the NHS....must be prepared to accept patients -or users- as partners (Jay 1998).

It is becoming accepted that research undertaken to establish the evidence for the provision of user-centred services must itself be user-centred. In this way the move to encourage the development of evidence based practice in the NHS has also helped to direct more attention to the views of service users and to the development of appropriate research methods. However such developments are not unproblematic and it is possible that social research may itself add to the discrimination and exclusion that service users feel if it adopts approaches which continue to marginalise or distort their experiences.

Chapter 5 of the thesis considered the social research context in which the fieldwork for this study was undertaken. Any attempt to access, understand and report upon other people's worlds and experiences is bound to be fraught with difficulties, for there can be no direct access to other people's lives. For a study such as this one, which has a strong commitment to retaining its participants' voices, these difficulties are particularly acute. The study adopts the view that social reality is many faceted and changing and that any data produced in the study of it will be created through the interaction of the researcher and the participants. Furthermore it accepts that language is not a transparent medium, giving direct access to other people's experiences, but rather that language itself helps to constitute that experience. Consequently the study is based upon an idealist ontology and an interpretivist epistemology and adopted a non-standardised, feminist, qualitative and grounded theory approach, as being best suited to developing an understanding of active individuals' pre-interpreted experience (Harding 1991) (Stanley & Wise 1993) (Maynard & Purvis 1994).

The study followed Mishler in regarding research interviews as speech events (Mishler 1986) and the series of interviews undertaken with each participant adopted an unstructured format and aimed to allow the participants to bring forward their own stories, meanings and concerns, in their own time and their own terms, rather than confronting them with a set of pre-defined research questions. However it became clear that this commitment to participants' own perceptions and interpretations must extend beyond the conduct of the interviews themselves into their recording, analysis and writing up. This transition from interview talk to research report text is never a simple matter and the decisions taken throughout a study with regard to recording, transcription, analysis and presentation are all part of the study's interpretive practice and have important implications for how much of whose voice can be heard in the study's findings (Devault 1990) (Reissman 1993) (Richardson 1994). Just as the study's data are not simply lying "out there" waiting to be collected, so too analysis is never merely a mechanical or technical task but rather part of the researcher's own interpretation and re-creation of the participants' social worlds. Consequently this study transcribed interviews into both prose and poetry and employed both narrative analysis and coding schemes aided by the Nud.ist software programme in an effort to remain open and responsive to all the various types of data generated by the interviews. It also experimented with a variety of formats, not all of them textual, for the re-presentation of its findings.

10.4.1 Implications for future research

In all of this, possession of the power to "name" is crucial, whether in policy, practice or social research. The ways in which mental distress has been defined, and by whom, have had terrible repercussions for these service users. For centuries their lives have been described, and prescribed, by others. Returning to them the power to name and define their own experience and to have those definitions acknowledged and acted upon would have huge implications.

For researchers this would mean a constant re-examination of the approaches adopted and of the decisions taken throughout any project concerned with service users' experiences in order to ensure their more accurate interpretation and presentation and less attempts to fit their words and stories into inappropriate names and categories or to privilege the needs of research projects over those of their participants. It would also entail relationships between researchers and participants that respect and value the latter's concerns and knowledge and enhance their self esteem. It would re-position social research from a space that fits the interests and needs of agencies and providers to one that fits the needs of its participants. It would make research part of their solution rather than part of their problem. For surely one of the major purposes of social scientific investigation of policy issues is the development of just such different perspectives, based upon different voices than those usually heard.

For, if we recognise that all knowledge is produced by and within structures of power and politics, it is clear that a knowledge of severe mental illness that started from the experiences of those who live with it would produce very different theories and policies than those produced mainly by white, professional, "sane" men. A mental health service designed by these service users would be based upon a broad social and structural template, rather than a narrow, medical and individual one, and so look very different from the one currently provided for them. Service users need to be granted the time, resources and networks to develop such knowledge and challenge the existing suppositions. They could thus develop their own story of mental illness. A story that would change all our lives.

10.5 Conclusions

This thesis has, as promised, been concerned with stories and spaces, with uncertainty and confusion. It has gathered together in one place an imposing collection of contested terms and ambiguous concepts; community, need,

power, care, mental illness, empowerment.....

The common themes that unite all three sections of this thesis[the discussion of mental health policy in Chapters Two - Four; the consideration of the theory and methods of social research in Chapter Five; and the accounts of service users' experience of severe mental illness in Chapters Six - Nine] are those of uncertainty and contradiction. Those with the power to decide mental health policy have been, and still are, themselves uncertain what insanity/ madness/ mental illness/ mental distress is, where it should be and what should be done about it. Consequently the physical, moral, social and economic spaces that our society has provided for it have always been contested and ambiguous, for they contain competing and contradictory designs, pressures and hopes.

In addition, the perspective of those who live with mental illness has, until recently, been excluded from the debate and, thus, from decisions about these shapes and spaces; shapes and spaces which say as much about the society from which they have sprung as they do about madness at that time. Service users therefore find themselves and their lives both in and structured by these very uncertain spaces. Their experience, as they make decisions and judgments to manage their daily lives in these difficult circumstances, can thus be seen as one of being "lost in space".

In the sphere of social research likewise, research that aims to access, interpret, analyse and theorize the experiences and accounts of other people will also face much uncertainty and many dilemmas, both practical and theoretical. Studies such as this one, which try to retain their participants' voices in research reports for academic and policy audiences, are, like the service users who participated in it, in disputed spaces. They must try to fit the demands of both worlds. They must try to find ways both to hear what is said about private, personal lives and to re-present that as public knowledge without mis-shaping its meanings, for research categories and discourses can also prove a very poor fit for service users' experiences, thus again leaving them "lost in space".

This analysis contributes to the sociology of mental illness by explicitly considering service users' experiences and the implication of inadequate social research approaches and methods in their continuing exclusion from the debate. In the nineteenth century people with severe mental illnesses were excluded from society and removed into the asylum not only because there was no other physical place for them but also, and inextricably linked to that, because there was no moral, social or economic place for them. In the twentieth century, we may have made some changes in order to re-provide physical sites for mental illness back in the community, but we have certainly not been prepared to all move over a little to provide moral, social and eco-

nomic spaces that are a comfortable fit for all. The dominant voices shaping such spaces continue to be those of mental health professionals and policy makers, not those who live with mental ill health, whose voices and tales remain "lost in space".

APPENDIX

A. THE INTERVIEW TIMETABLE

The interview timetable was as follows;

April 1996, 5 interviews

- 1] User group 1. Eric, Linda, Gary, Mary. Day centre. Taped. One and a half hours.
- 2] West of county Jane, first interview. At home. Taped. 45 minutes.
- 3] User group 2. John, Gary, Barry, Linda. Day centre. Taped. 2 hours.
- 4] North of county Irene and Dennis, her husband, first interview. At home. Taped. 2 hours.
- 5] West of county Jane, second interview. At home. Taped. 45 minutes.

May 1996, 5 interviews

- 6] User group 3. Barry, Linda, Eric, Gary, John. Day centre. Taped. One and a half hours.
- 7] North of county Irene and Dennis, second interview. At home. Taped. 2 hours.
- 8] North of county Carole, first interview. At home. Taped. One hour and fifteen minutes.
- 9] North of county Harry, first interview. At home. Notes.[Harry was very anxious and already had the radio on.] 1 hour.
- 10] West of county Mark, first interview. At home. Taped. 1 hour. Mid county Barry, first interview. Day centre. Taped. 1 hour.

June 1996, 4 interviews

- 11] North of county Carole, second interview. At home. Notes.[Carole read through the transcript from the first interview and then decided not to be taped again.] 45 minutes.

- 12] User group 4. Barry, Eric, John, Tim. Day centre. Taped. 2 hours.
- 13] West of county Mark, second interview. At home. Notes.[The first taping had not been very successful. Mark was happier without.] 1 hour.
- 14] North of county Harry, second interview. At home. Notes. 45 minutes.

July 1996, 4 interviews

- 15] User group 5. Linda and her young daughter, John, Eric, Tim. Day centre. Taped. One and a half hours.
- 16] North of county Joseph and his neighbour, first interview. At home. Notes. [Joseph and his neighbour immediately launched into their stories. No obvious place to plug in.] One and a half hours.
- 17] North of county Harry, third interview. At home. Notes. 45 minutes.
- 18] West of county Mark, third interview. At home. Notes. 45 minutes.

August 1996, 2 interviews

- 19] User group 6. Barry, Gary, John. Day centre. Taped. 2 hours.
- 20] North of county Joseph, second interview. At home. Notes. One and a half hours.

September 1996, 3 interviews

- 21] North of county Joseph, third interview. At home. Notes. 1 hour.
- 22] User group 7. Tim, Barry, Mary, John, Jeff -advocacy worker, invited to join by group. Day centre. Taped. Two and a half hours.
- 23] West of county Jane, third interview. At home. Notes. [Jane did not want to be taped.] 45 minutes.

October 1996, 6 interviews

- 24] Sheltered employment Mabel, first interview. Manager's office. Taped. 1 hour.
- 25] Sheltered employment Matthew, first interview. Manager's office. Taped. 45 minutes.

- 26] Sheltered employment George, first interview. Workers' rest room. Notes [impossible to tape in there. No plugs. Too exposed.] 45 minutes.
- 27] Sheltered employment Mike, first interview. Manager's office. Taped. 1 hour.
- 28] Sheltered employment Paul, first interview. Manager's office. Taped. 45 minutes.
- 29] Sheltered employment Lenny, first interview. Manager's office. Taped. 1 hour.

November 1996, 8 interviews

- 30] Sheltered employment Mabel, second interview. Manager's office. Taped. 1 hour.
- 31] Sheltered employment Matthew, second interview. Manager's office. Taped. 1 hour.
- 32] Sheltered employment George, second interview. Workers' rest room. Notes. 30 minutes.
- 33] Sheltered employment Mike, second interview. Manager's office. Taped. 1 hour.
- 34] Sheltered employment Paul, second interview. Manager's office. Taped. 45 minutes.
- 35] Sheltered employment Lenny, second interview. Manager's office. Taped. 1 hour.
- 36] Hospital site Darren, first interview. House/ward. Notes. 1 hour.
- 37] Hospital site Ian, first interview. House/ward. Taped. 2 hours.

December 1996, 8 interviews

- 38] Sheltered employment Mabel, third interview. Manager's office. Taped. 1 hour.
- 39] Sheltered employment Matthew, third interview. Manager's office. Taped. 1 hour.
- 40] Sheltered employment George, third interview. Workers' rest room. Taped. 30 minutes.

- 41] Hospital site Ian, second interview. House/ward. Taped. One and a half hours.
- 42] Hospital site Darren, second interview. House/ward. Notes. 45 minutes.
- 43] Sheltered employment Mike, third interview. Manager's office. Taped. 1 hour.
- 44] Sheltered employment Paul, third interview. Manager's office. Taped. 45 minutes.
- 45] Sheltered employment Lenny, third interview. Manager's office. Taped. 1 hour.

January 1997, 1 interview

- 46] Hospital site Ian, third interview. House/ward. Taped. 2 hours.

February 1997, 1 interview

- 47] Hospital site Ian, fourth interview. House/ward. Taped. 2 hours.

B. IAN'S ACCOUNT OF HIS ILLNESS

IAN TWO ; the tale of the first illness.

p.3.

1] I was just standing around at the time
2] And the voices just came
3] right out at us.

4] I would just be there
5] with a record on
6] listening to the music
7] And the voices came out !!

8] I went into a trance
9] I remember that.
10] I just started getting transfixed by the music.

11] It kept happening,
12] for months, and months, and months.
13] And I didn't know what it was
14] And I was worried about it.

15] My mother thought I was on drugs
16] And they got a bit worried
17] And they locked us in the house,
18] Thinking I was taking drugs.

19] And I kept saying
20] That I wasn't taking drugs
21] And they kept saying
22] "Well, what's the matter with you then?"
23] And I kept saying
24] "I don't know...."

25] And eventually I got to see a psychiatrist.
26] And as soon as she started asking us questions
27] I just sat at a table
28] telling her what was going on
29] And she was asking me all these strange questions,
30] I thought they were strange questions
31] But she seemed to know
32] what was going on.
33] And that was it.
34] I was here !!

35] Because she had asked me those right questions
36] That nobody had ever asked us before.
37] They hadn't asked the right questions
38] And so I couldn't tell them.

39] The GP referred us to the psychiatrist
40] because I was going back to the doctor's
41] three or four times a week.
42] And he was asking us questions like
43] "Are you gay?"
44] And I was saying
45] "NO !"
46] And I was telling him.
47] And I started crying in his room.

48] And one time I was ill,
49] [because I used to live in a club,
50] my mum and dad were the club steward and stewardess]
51] And one day I was playing pool
52] In the pool room after hours
53] And I started crying my eyes out,
54] In the pool room.
55] And the next thing I knew
56] The doctor was there
57] At one o'clock in the morning.
58] And he went through his bag
59] And he give us some tablets.
60] He started us off on these tablets
61] And referred us to the psychiatrist.

62] And that took two weeks.

63] She gave us the opportunity.
63] She said,
65] "You can come in,
66] For a couple of days, or whatever.
67] Just while we get you sorted out."
68] And I said,
69] "What hospital would that be?"
70] And she said,
71] "This psychiatric hospital."
72] Which was a bit of a shock to us.

73] And she said it would be
74] Just for a couple of days.

75] But I was in six months !!

76] They always say that,
77] That it's a couple of days.

78] But it's a long time !

p.4.

79] I was bad when I first come in,
80] Hearing voices and that.
81] And crying a lot.

82] I was really not well.

83] And that first week or so
84] I wasn't having any medication at all
85] What they were doing was
86] Just feeding us with meals.

87] Just to build up my strength, I think.

88] And then the doctor came to see us,
89] And he said,
90] "I want to start you on some treatment.
91] Give you some tablets,
92] And get all these nasty voices taken away."

93] And I said,
94["Oh. I suppose."
95] And he got us to sign some pieces of paper,
96] So that they could start the treatment.

97] And so I signed it!

98] And then he asked us lots of questions,
99] And asked whether I wanted to start
100] on medication
101] or the electric shock therapy.

102] Then he told us all about
103] the electric shock treatment
104] And then he told us about
105] the tablet form of medication.
106] And I signed for the tablet form.

107] I didn't want the electric shock treatment !

108] And so then they started us
109] On the tablets.
110] [Well, actually I had tablets, the first night I was in.
111] I had sleeping tablets,
112] So I could get a good sleep]

113] And then they started us
114] On injections,
115] a week later.

116] And about three weeks after that
117] The voices were starting to go away.

118] After my fourth injection
119] The voices went away completely.

120] And that was very nice !!

C. FIELDWORK PAPERS

RESEARCH PROJECT ;THE CHANGEOVER TO COMMUNITY CARE

My name is Marilyn Kendall. I work at Durham University and am studying mental health services, especially the recent changeover to community care.

I am looking at the ways in which this change and the closing down of the old long stay hospitals has affected the lives of people who use these services. It is important to know whether and in what ways such changes seem to you to be for the better and whether they do help people to receive the kind of help that they feel they need.

I am writing to ask if you would be willing to take part in my enquiry by spending some time telling me about your experiences of and views on the mental health services in Northumberland. It is now recognised that the people who use the services have important insights into their personal needs and should be more involved in decisions about their care. In order to provide the best possible services in ways that meet people's needs we need to know more about what it feels like to receive psychiatric treatment and care. There are no forms to fill in or set questions to answer. I am simply interested in knowing more about your experiences.

I am an independent researcher, not employed by the Health or Social Services, although this study does have their support and co-operation . This letter has been given to you through staff in order to protect your confidentiality; I have not been given your name or address.

Let me reassure that, if you do decide to take part in the study, none of the personal information that you give will be made available to staff. It is important to report back to you and to them the findings of the study in a generalised way, but all the information collected will be kept strictly confidential and anonymous.The findings from the study will be written up into a report but no individuals will be identified in it.

Furthermore you should know that any care and treatment you may be receiving will not be affected in any way by your decision on whether or not to take part in this study..

I do hope that you will seriously consider giving your help as your knowledge and experience would be most valuable. If you would like more information before deciding, then please get in touch with me either by returning the enclosed letter or by telephoning me on this number ... 01434 600015

If you already feel that you are willing to take part, please return the enclosed letter or telephone me direct on .... 01434 600015 and I will arrange to meet with you.

Best wishes,

Marilyn Kendall

Dear Marilyn,

I have read your letter about the research project on the changeover to community care.
*I would like more information about it before I decide whether or not to take part.

*I would like to take part in the project.

*Please cross out whichever does not apply.

NAME. .....

DATE. .....

ADDRESS. .....

.....

.....

.....

TELEPHONE NUMBER. .....

LOCAL RESEARCH ETHICS COMMITTEE

CONSENT FORM FOR AN ADULT TO TAKE PART IN RESEARCH

Name of Research Project: Of Peoples Policies - Community Care

Name of Researcher: Marilyn Kendall

Name of Participant: X

I consent to take part in this research project.

I understand that the research is designed to add to medical knowledge.

I have read the note of explanation about the study that is attached and I have had time to think about it.

I have had the study explained to me by Marilyn Kendall

I have been told that I can withdraw my consent at any stage without giving reason, and without prejudice to my treatment.

I have been given a copy of this Consent Form.

Signed X Date .....

I can confirm that I have explained to the participant the nature of this study. and have given adequate time to answer any questions concerning it.

Signed: M L Kendall Date: .....

Name (in capitals) MARILYN KENDALL

Post: RESEARCHER - DURHAM UNIVERSITY

BLACKTHICK COM

Outline for Interviews

Preamble
Introduction -independence of researcher -explanation of purpose and structure of the research -agreement to take part and on methods of recording to be used - stress on confidentiality and anonymity -use to be made of the material -stress on freedom to stop the interview at any point or to move on to other topics -stress on no direct effect on care and treatment.

1. Typical Day
Perhaps you could begin by telling me about a typical day for you now?
timescale, -events, -housing, -employment, -transport, -material circumstances, -contacts, -important relationships, -social contacts and activities, -sources of support, -sources of pleasure, -problem areas, -contact with psychiatric services and treatments, -things would like to be different.

explanations, -information, -communication, -choice, -advocacy, -involvement, -decision making.

2.Untypical times
holidays, -birthdays,-Christmas,-evenings,-weekends,-crisis times.

3. Past experiences.
typical and untypical times then, -comparison with now, -experiences of other psychiatric services and treatments.

4. Initial contact.
how first came to be in contact with the psychiatric services, -decision making process then,-impact on life, -perceptions and reflections.

5. The future.
hopes and aspirations, -what would be needed to achieve them.

6. Any other points.

Feedback from any earlier interviews, opportunities to amend, correct, add onto or delete earlier accounts.

Check back over this interview.
Arrangements for next one.

Thanks for and acknowledgement of contribution.
Check got contact number.

General observations
Scope and duration of interviews generally determined by concerns of respondents.
Questioning from researcher usually open-ended and non-directive, e.g. could you tell me a bit more about? -can you explain to me..? -why? -how? -when? -where? -why? -how much? -how often? -what?
Importance of careful, attentive and analytic listening.
Address respondent's feelings, values, perceptions and meanings.
Exploratory, allow voices of participants to be heard.
Descriptions and explanations amplified and focus of research refined during and in the light of the progress of the study.

D. NUD.IST CODING TREE

Nodes 135

Q.S.R. NUD.IST Power version, revision 3.0.4d GUI.
Licensee: Department of Sociology, Durham University.

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(1 6 5)	/interviewees/speakers/linda
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(2 1 1 5)	/policies/mental illness/course of the illness/readmissions
(2 1 2)	/policies/mental illness/type of illness
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Nodes

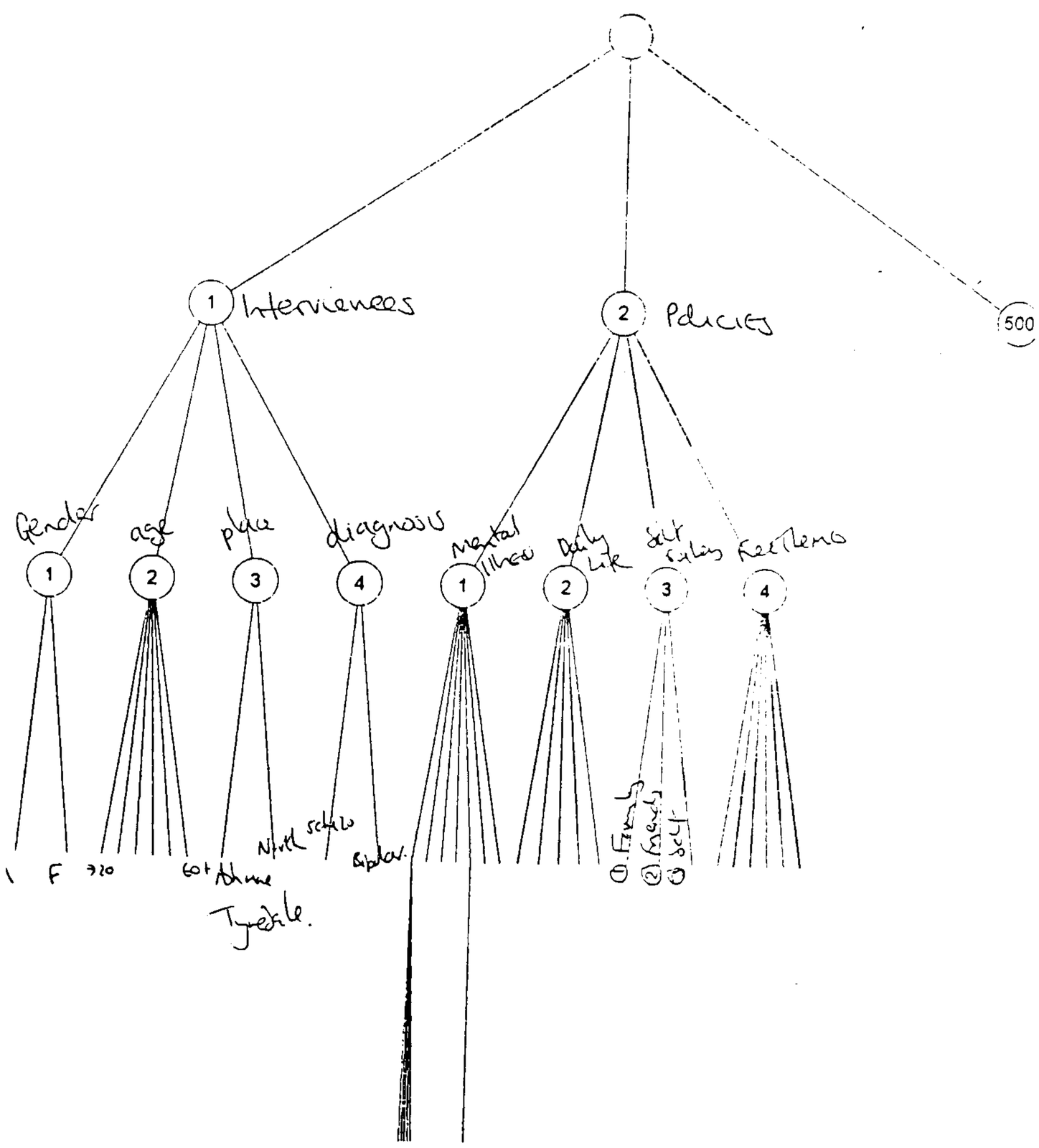
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Nodes

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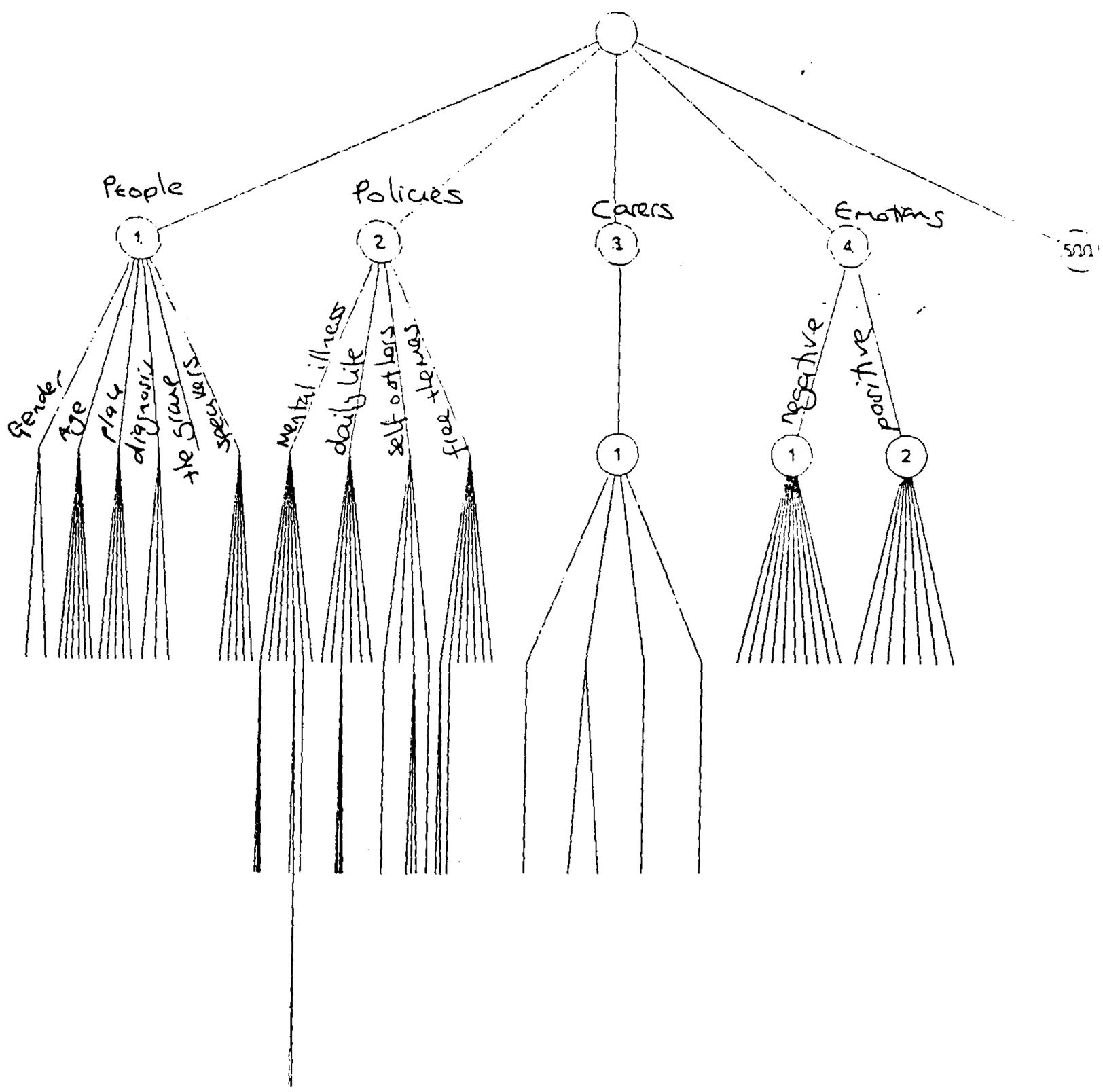
27th July '97

Nud·ist Coding Tree



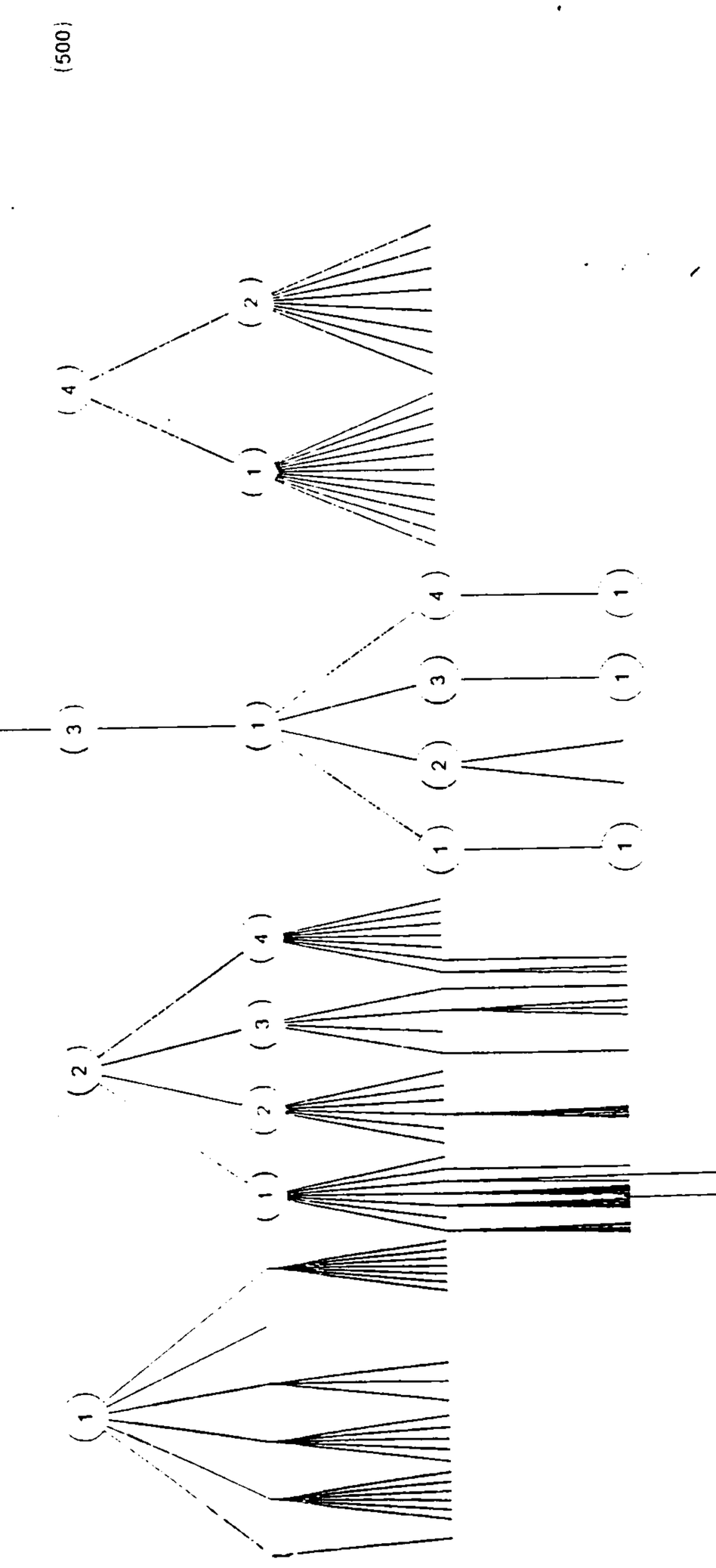
Nud·ist Coding Tree

15-10-97
113 nodes



137 nodes

Nud·ist Coding Tree



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